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The social construction of a mother's identity amidst the confluence of motherhood discourses

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The social construction of a mother's identity amidst the confluence of motherhood discourses

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The social construction of a mother's identity amidst the confluence of motherhood discourses

Abstract

Motherhood is understood as a site of conflicting socially constructed discourses. Mothers find themselves subjected to a multitude of discourses which, when deconstructed, reveal the cultural norms and expectations of mothers, underpinned by the moral orders and values of society. This dissertation focuses specifically on the discourses about mothers whose children are considered different and in difficulty. I draw on my own experience as a mother of a child considered different and how I negotiated and narrated my identity within various culturally available discourses, a practice which allows me to be seen as populated by a multitude of selves.

In addition, the world of mothers with children considered different is opened up to our critical gaze. I discuss the way the dominant medical discourse about mothers has permeated the professions linked to children, and the possible effects this discourse has upon mothers. I describe various formulations of the medical discourse, such as lack of support and criticism, and its effects, through stories of mothers whose children have been diagnosed with the disputed learning disability Attention Deficit Hyperactivity Disorder (ADHD) in the French speaking region of Switzerland. Mothers negotiate and narrate their identity through positive re-storying and acts of resistance.

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As you can see, this dissertation is relationally constructed ...

Prologue

“Just having a diagnosis,” one patient said, “means the rest of your life can start.”

Kathryn Montgomery, *How doctors think*, 2006:65

My son, Edward, came round to see me at home one day in April 2012. He came by bike. It is his preferred means of transport. He has a fixed gear bike that he calls “Jack”. It is white with a sign “one less car” on it. In contrast, he wears black jeans and a black, sleeveless t-shirt, and black studs in his earlobes. On his left upper arm, he has a British flag tattooed and on his right upper arm, he has his most recent tattoo done in Bangkok of three lotus flowers. One flower is for his sister, Bea, and one is for me, he told us. On the inside of his left forearm, he has three letters tattooed: XXY.

Edward was diagnosed shortly before his sixteenth birthday with the chromosomal aneuploidy of ‘XXY’. The endocrinologist, Dr. S., said to me that day that even without the blood test results he was ninety-nine per cent sure that my son had this syndrome. That day another doctor, Harry Klinefelter, appeared in our lives and my son became a “Klinefelter” boy. Klinefelter syndrome was described by Harry Klinefelter in 1942 as an endocrinal problem, i.e. a lack of the masculine hormone testosterone in a group of young men, although it was later recognised that these men had an additional X chromosome (Klinefelter, 1986). Not all people with XXY are considered men, or have Klinefelter syndrome. Some of them are considered to be intersexed (Harper, 2007). All would be considered as having a Disorder of Sexual Development, a “DSD” (Intersex Society of North America, 2006). The term “DSD” is under much debate amongst people affected by such conditions, as it is consider pejorative. The preferred term for these people and many of their associated practitioners is “Variation of Sexual Development.”ⁱ

As like many other people we were initially relieved to have a diagnosis. It was an answer to the question, “why is Edward different from other boys his age?” In his early years he was considered difficult by friends and family members. I was told that I had the patience of an angel. His school path was chaotic; he was diagnosed as having Attention Deficit Hyperactivity Disorder (ADHD) at the age of 10, and went from mainstream public school to special educational needs class, and then to one private school after another, and gave up school after his Klinefelter diagnosis at the age of 16.

Having a diagnosis is often the start of treatment which will ‘cure’ the patient. For us, it was the beginning of three years of suffering and torment, during which I wondered whether he would continue to live.

Today, at the age of 28, my son has a way of looking at the world, a compassion for those who are less fortunate, an understanding of how he is, of what he likes,

that many of his contemporaries don't have. In my professional work I train and coach young people his age in the corporate world, and I sometimes find myself comparing them, and wondering how it could be that my son should be considered un-able or dis-abled. Perhaps his story confirms the "social model" of disability (Shakespeare, 2006), which would say that Edward is more disabled by society's response to him than by Klinefelter syndrome. Not having a diagnosis not only reduced access to educational and other support activities, it placed, to a large degree, the "responsibility" for his lack of scholastic ability with me, his mother. Various reports by teachers and state agencies described me as "the over-protective mother," "in marital conflict," and later "divorced" who had a "difficult relationship" with my son. Whenever I asked for support for him, I faced psychiatrists who told me that I should stop looking for a medical explanation for my son's difficulties, and start doing my own personal therapeutic work.

When I asked for Edward's permission to write my doctoral dissertation on our lives in June 2009, he replied, "Cool, just wait until I tell my friends my mother is writing a book about me." I had hoped that we would have co-authored this inquiry. It hasn't worked out that way. However we have our way of having short conversations about things that matter. One such conversation was in July 2010 when we were driving home together from the mountains with his cat, Batty, protesting loudly at being locked in a cage on the backseat. I told him that I had been interviewing mothers whose children were diagnosed with ADHD, and how interesting it was to hear how they had similar experiences to ours. I asked him if he would like to interview the children of these mothers and hear their story. He replied that he didn't want to because he had a hard time thinking about those times. He felt that he had been so difficult and caused me so much grief. I don't want him to feel guilt or shame for those times. I tried to think of a way that we could look at what happened in a different light. So I asked him if he thought that he had grown stronger in difficult times or hardship, and he answered yes. "So," I said, "then I have grown stronger too." If we have grown and developed in certain ways, then the way we are today reflects those times. We can only be who we are through our experience and our relationships. We agreed that we both liked the way we are today. Our moods lightened. But I also told him that although he may feel guilty for his behaviour towards me, I also feel guilty for not having done enough, for not having been able to protect him. He was a little surprised. I suggested that our goal would be to work through this inquiry and no longer feel guilty, and he agreed to that.

As time has gone on, and the story has been written, I have asked him to think about alternatives to the assistance we received. Another day, May 2 2012, I asked him if we could think of ways in which the social assistant, Mrs. H. and the psychiatrist, Dr. H., could have helped us more when he attended a therapeutic center the year following his diagnosis. I said that I thought that they had focused on him leaving home to live in a "foyer" (place of residence for young people) as the only possibility, at the age of 17. They couldn't understand

why I wanted to keep him at home. Edward started talking angrily about these two professionals. After a few minutes, I asked him again, “what could they have done differently? From my point of view, I wanted them to help me figure out what I could do to help you.” He said, “they never asked me to think of how I could help you. They never held me responsible for my actions.” “So,” I said, “they didn’t help us to negotiate how we could go on living together?” “Yes,” he said, “they didn’t help us to do that. You have your answer, Mummy.”

Chapter 1: The starting point revisited

“Telling a story about oneself is not the same as giving an account of oneself”
Judith Butler, *Giving an account of oneself*, 2005:12

In this chapter I position my dissertation as a constructionist (Gergen, 2009) autoethnographic account. I describe the topic of my inquiry, my thoughts about the importance of this dissertation and its applicability for various audiences.

1.1 Introduction to an autoethnographic account

As I have said in the acknowledgements, there are many journeys contained in this dissertation. Of great importance is the journey that I have made from understanding what I thought was a personal problem to understanding that it was shared by others. By inquiring into other mothers’ experiences, I came to see that, although we lived our experiences in a very personal and individual - even isolated – manner, we can form a community. Hanisch (1970) talks of how we can be persuaded through psychology and sociology that our dilemmas are our own personal issue, one that requires self-confidence and assertiveness to be dealt with, and that what some women experience and call oppression is a political issue. Dillon (2011) writes that although our experiences, feelings and possibilities feel personal, they “are limited, moulded, defined and delimited by the broader and social context” (2011: 141).

The dilemma that I have inquired into is about how we, as a society, help mothers who have children who are considered different. Perhaps I should say, how we do not help mothers who have children who are considered different. Perhaps another way of wording the inquiry is to look at how it seems that we only help some mothers when it has been established, by the scientific or medical community, that it is not the mothers’ way of behaving that has led their children to be different.

In my autoethnographic account, I seek to give a personal account of how I have experienced my journey of motherhood. This journey is not simply about me, but about all the relationships I have had within various contexts, and the beliefs that people hold that some would call “norms.” Butler writes, “the ‘I’ has no story of its own that is not also the story of a relation – or set of relations – to a set of norms” (Butler, 2005: 8). Therefore, this account goes beyond the telling of my story and my interpretations of the relations I had with other people. This account attempts to render visible the invisible norms or standards that we have constructed around motherhood, and in particular when mothers have children who are considered different.

This inquiry is positioned within the Social Constructionism of Gergen and the Taos Institute doctoral program run in conjunction with the Tilburg University. Gergen and Gergen (2003: 15) write, “Social constructionist inquiry is principally concerned with explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live.” In Chapter Two I will describe the tenets of this form of social construction.

1.2. The internal tensions of my motherhood experience

In the prologue I briefly explained about my son’s two diagnoses, the first of ADHD and the second of Klinefelter. The quote from Montgomery that once you have a diagnosis “the rest of your life can start” implies that from the moment you know what illness you are suffering from, you are on your way to be cured. You will regain your original state or, if particularly lucky, a normal state. When your child is different, he or she has, perhaps, a different normal state. I find it hard to convey what I want to tell you about without describing my child as not normal, as abnormal. I want to tell you that my child did not fit the norms expected of children. I did not experience my child as not normal. I experienced him sometimes as slightly rebellious and different, but I found his way of doing things as interesting, inventive and charming. However, he didn’t fit in at school. He didn’t fit according to the child psychiatrists, and it was disconcerting to be told that someone you are so familiar with is strange. Not fitting in, being told he was different, did not lead to him fitting in any better.

And often, as you will discover, my experience was one of being blamed for my son not fitting in, or not getting better. Perhaps, as a result, I find myself in a state of internal conflict or tension. Part of me, that seems to have a voice, says to me, that if I really accepted Edward for the way he is, I would not want him to be otherwise. I would not have minded that he didn’t fit in. This part says, he is how he is because of what he has been through. And truly I am proud of my good-looking son with his sleek, black jeans and t-shirts, his ear-studs and his tattoos, with his alternative worldview.

Part of me also blames myself for not doing enough to help him. This voice tells me that I didn’t find the right professionals or that I put too much trust in some professionals who were proven wrong. It holds me guilty for not having done enough and ashamed for not being good enough. It has had a lot to say during this inquiry, and yet when I read what I had done, I found that I had done so many things.

Part of me is angry with those who claimed that they were there to help us with professional support and services, and whose theories and practices did not help. That part of me tells me a story that if Edward had been helped through school, perhaps come to accept his difference and compensate for it, he would fit into our society better. He would meet the requirements of success in

today's Western world; he would have a profession hold down a job and have a long-standing romantic relationship. This voice insists that I have every right to be angry with the professionals for having denied him those possibilities.

These different parts of me are perseverant in getting my attention and ruminating for hours. They have spoiled many a day. If I don't pay attention to them, they don't stop. I have learned to write down what each part of me, each voice says. I even question the part of me that has such strong opinions. It seems to quieten the voice down when I write down what it has to say and inquire more. It is as if having its say, it feels that I have listened to it and is reassured that I will take it into consideration. I find it rather uncomfortable to have opposing thoughts that jostle for my attention. In psychological terms opposing thoughts are very often called "cognitive dissonance" (Festinger, 1965) and are supposed to cause a variety of feelings, such as anger, frustration or sadness.

This is my personal experience. When I started my inquiry, I hadn't paid attention to these different feelings and thoughts that made up these parts of me. I thought that I was alone in being so dispersed and confused. When I started to talk to the other mothers I found them telling me similar stories, how they found their children delightful and energetic until they encountered professionals who told them their children were strange. They also battled with their conflicting thoughts which they kept to themselves. To be called "cognitively dissonant" is to tell us that we are strange, perhaps mentally disabled. Our experience is that we are often told that it is because we are depressed, hyperactive or cognitively dissonant, that our children are the way they are. Perhaps there is a correlation between our feelings and our experience of our daily encounters. In scientific terms we may call this cause-and-effect, however social construction is not interested in this type of positioning. Social construction may even playfully ask whether it wouldn't be the other way around. Perhaps mothers become depressed when they cannot cope with what society expects of them.

1.3. Inquiring into others' experience and other ways of explicating our accounts

During this inquiry of others' experience and reading of theories on motherhood I came to pay attention to the insidious opinions about mothers in general and mothers of different children in particular. It was partly in response to the mothers' stories and focus on interactions with professionals that my dissertation has taken me to inquire more about these interactions, rather than interactions with partners, children or other family members. I learned about the notion of discourses or dominant cultural messages (Weingarten, 1998: 9). Our everyday talk is littered with medical, psychological and educational terms, associated with scientific truths, which focus on deficiencies and pathologies of mothers. I came to understand how my internal dialogue, those perseverant

thoughts, were the incorporations of those dominant discourses. I was even surprised to find that I too could maintain such discourses.

I also found other ways of explicating ourselves through social construction which considers that we are created through our relationships. I found ways of looking at those dominant discourses that allowed me to take distance, and to consider whether they were aligned with the practices that I give importance to. This hopefully has allowed me to transform those angry, guilty, blaming voices into an enlightened voice. It seems to me that by deconstructing the dominant discourses about motherhood, I have been able to diminish the power and the clamouring of my internal dialogue, to start to assist other mothers in doing the same. Perhaps I will be more daring and become politically involved in the defence of mothers.

1.4. The difference of children addressed in this dissertation

When I talk of children who are positioned as being different, I am drawing your attention to an important point about medical terms, diagnoses and the labelling of children who do not conform to the expectations of professionals who surround parents and their children from infancy onwards. The terms used to describe children who are positioned as being different are very often couched in medical terms, and describe these children's characteristics and deficiencies. It is hard to imagine that medical books or magazines would describe these children in positive, strength-based language. Solomon writes that even the terms used by the medical community such as "illness, syndrome, condition," which have supplanted other words, such as disorder, defect, abnormality, are "almost equally pejorative in their discreet way" (ibid:4-5). I would prefer to simply use the term "different" throughout my work. However, my work looks at two particular types of differences that children may have. The first is Attention Deficit and Hyperactivity Disorder (ADHD) and the second is Klinefelter Syndrome. There are a number of reasons why this body of work addresses these two differences. The first is that my son's genetic condition, Klinefelter Syndrome, was hidden by the focus on his ADHD diagnosis, and that may be a common occurrence. Our family doctor, Dr. C., told me that Edward was the third teenager he had seen in a year (i.e. 2000/2001) who had been originally diagnosed with ADHD and subsequently with Klinefelter Syndrome. A study on boys and adolescents with Klinefelter Syndrome done in the Netherlands by Bruining et al (2009) concluded that all boys with behavioural and cognitive difficulties should be tested for Klinefelter Syndrome. The second reason is that both differences are invisible. The children who are diagnosed with ADHD and Klinefelter Syndrome have no significant bodily markers that would make them easily identifiable, such as Trisomy 21, commonly known as Down's syndrome. Weingarten (1999, 2012) informs us about the "politics of illness narratives," and describes the differences between having an illness like breast cancer and Chronic Fatigue

Syndrome. She says there is little social and medical support for an invisible illness, such as Chronic Fatigue Syndrome, because its etiology is unknown, and for other reasons. Although Klinefelter Syndrome does have physical markers, they do not appear until the age of puberty. The third reason, related to the invisibility of physical markers, is that these children's mothers are submitted to similar discourses about motherhood. Today I know one mother whose son has a form of mosaic Klinefelter Syndrome who will not meet me in public to talk about her son for fear of being overheard and identified. The doctors who know these mothers do their job of guardian of confidentiality and privacy. Therefore I could not talk to these mothers about their experience. However, I did have the trust and opportunity to talk with a group of mothers about their experience of having a different child who was diagnosed with ADHD. We all heard similar remarks, some helpful and some unhelpful, from professionals and family members about our way of mothering our different children, and we all had recourse to medical advice and treatment for our children. These remarks form to some extent the cultural discourses of motherhood.

1.5. My thoughts about the importance of this dissertation

As mothers we are continuously faced with remarks that describe how we should be and how we ought to raise our children. These remarks hold us responsible for what our children are like. This could be described as operating within a particular dominant discourse. These messages are ubiquitous; they are held by persons like our children's fathers, our parents, the people at the child-care centre, the teachers in schools, and the medical professionals. We, as mothers, also tend to hold them. They contain the norms and the expectations that mothers should live up to. Some of them are in direct opposition to each other. Sometimes we don't notice how we pile them up, so that they create impossible goals to achieve. If the mothers don't measure up to the expectations, if they don't live up to the norm to which we hold them accountable, then they may pay the price of being to blame. Sometimes there is no mistake to feel guilty about, in its place there is an overwhelming feeling of not being good enough that some call shame. This shame invites us to hide from the gaze of others; it encourages us to shrivel up and constricts our movements and thoughts. It can do damage to our relationships, including those we have with our children. It can damage our sense of self, or our self-identity (Giddens, 1991:65). I talk more about this experience of shame in Chapter Three. For some this is "mistaken shame," a shame that mothers can carry because they do not live up to the cultural expectations. If we are to help mothers who carry the heavier burden of raising children more than their partners or husbands, especially mothers whose children are different and need more attention than other children, then we need to become more attentive to what it is that we are conveying in our practices.

It is therefore important to inform the various audiences of this dissertation about the experiences of mothers so that together we can change our practices. Pearce (2007) writes that we should write and read ethnographies to learn about the ‘other’ in order to “stimulate the evolution of our own consciousness” (2007: 44).

1.6. This dissertation is for you

1.6.1. Writing for other parents

If it were not for a colleague at a workshop in June 2009, a mother with a different child in difficulty, I don’t know if this would have come about. She encouraged me to write about how Edward’s Mother, a particular part of me, came into being. I am pleased to be able to respond to her and other mothers. Frank writes, “People tell stories not just to work out their changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others – each must create his own – but rather to witness the experience of reconstructing one’s own map. Witnessing is one duty to the commonsensical and others” (Frank, 1995: 17).

I write for parents so that they can “see” the experiences of dominant cultural discourses on the way we are incited to raise our children in today’s Western society. I would say that holding mothers responsible for the children impoverishes our lives, rather than enriching them.

1.6.2. Writing for professionals

I write for the professionals who deal with mothers, fathers and their children, who may be tempted by the role of the expert underpinned by persuasive professional discourses to reduce their clients or patients to “serviceable others” (Sampson, 2008: 4). I write for the professionals who work with mothers and their children diagnosed with ADHD. I have written specifically about their experience in the French speaking region of Switzerland. I wonder how you will react to these stories of mothers’ experiences. I hope that the understanding of their experiences and my dissertation will work towards an improvement in support.

I also address the professional practitioners who work with the parents of children, unborn and born, with Variations of Sexual Development, VSD, formerly known and still described by many as Intersex conditions (Harper, 2007). VSDs are not as rare as many believe. The Turner Centre in Denmark claims that one in every five hundred and thirty-seven boys is born with Klinefelter syndrome. Variations of Sexual Development come in a variety of forms along the continuum between male and female, according to Dr. Michal Yaron of Geneva University Hospital (personal communication, August 2011). Sexual identity is not performed as simply as Money and Erhardt (1972) claimed it to be: a matter of surgical and hormonal intervention before the age

of three. As Edward says, most practitioners think that having hormonal substitution for his lack of naturally produced testosterone is sufficient, not just to avoid osteoporosis common to Klinefelter men, but in making him a male. He feels that “he has been dealt with”. But he says, the hormonal substitution does not address his question of whether he feels more male or female, and how he deals with his variation. To be in a world of sexual identity dichotomy, where the majority of people are either male or female, finding your place is not easy. It takes a lot of courage for someone like Phoebe (*Orchids, My intersex adventure*, 2010) to say, in front of the camera, “I’m both male and female.” It is not easy for any parent to know how to raise a different child. Most parents, like the general public, who have a child with one of the variations have such little knowledge, not because they are not common, but because the public is unaware. Supporting the parents of these children in helpful ways is one of the hopes I have for this work.

1.6.3. Writing for the academic community

Lastly, and not most unimportantly, I write, from a social constructionist stance, for the academic community about autoethnography and the deconstruction of discourses that have taken root in our cultures, and how we can go beyond awareness-raising to discuss possible transformative practices. I am both subject and object, speaking *fully* for myself – although I am populated by others - in the hope of gaining “the esteem of my peers” (Gergen, 2009: 236 and 237).

1.7. My hopes and dreams for this work

I hope that through this inquiry, my immersion in social constructionism and the training in Narrative therapy that I commenced during this time will assist me in finding alternative possibilities to help mothers who have children in difficulty, no matter what the difficulty, to help alleviate the grip that the experiences of what some call “guilt and shame” have on them.

I hope that this work may be read by professionals and academics, so that they may understand how motherhood can be experienced by mothers whose children are different.

I hope that I will continue to work together with some of the professionals, with whom I have already started to work, so that we can provide support for the mothers and fathers of children with Variations of Sexual Development. I hope that I will now have time to dedicate to the support group that I have initiated.

I hope that having written this dissertation I will no longer rant about the past events and experiences, nor allow them to overwhelm my thoughts in future dealings. I hope that I will be able to listen to the moral order of others and be able to understand the constraints within which they operate, and to find ways of connecting.

I hope that the ideas of social constructionism and, in particular, the ideas of multiple selves will become more available to the general public. I dream of the potential of poetic activism (Gergen, 2009).

1.8. The organisation of this dissertation

In Chapter One, the introduction to my inquiry, I hope that I have described the starting point of my journey, and the aspirations I have for this dissertation. I cannot say that I would have described the previous in the same way in June 2009, because in those days I did not know what I know today. As Smart (2007) says in her introduction, we often start writing without a goal in mind, and the writing helps to develop our ideas as we go along. As I have already mentioned, the interviews with the mothers who focused their stories on interactions with the professionals also led me to focus my inquiry on the permeation of the dominant medical discourse in society.

In Chapter Two, I will outline the philosophical stance and the premises of social construction that guide me in this dissertation. The philosophical stance of social constructionism allows me the alternative to writing an autobiography, of staying confined in a modernist, essentialist perspective. It provides me with a way of looking at how I position myself within my “motherhood,” within the relationships with professionals. I also address the notion of identity, as an alternative to focusing on the psychological notion of personality.

In Chapter Three, I present the methods of my inquiry. They are primarily autoethnography and narrative analysis. I also describe writing as a form of research, the use of method of voice dialogue which allowed me to develop a reflexive self, and the use I made of re-membering. I describe the step-by-step ways in which I went about this inquiry.

In Chapter Four, I present the cultural dominant discourses that mothers find themselves subjected to, and within which they narrate and negotiate their identity of mother, particularly, of a different child. I present the medical discourse as a dominant discourse which has permeated society, and has consequences, illustrated with three situations. Following this, I present a discourse about mothers’ well-being when they have children who are positioned as being different, particularly those with learning disabilities. This discourse is less known in society. I then present the possible effects of guilt and shame that mothers sometimes find themselves experiencing.

In Chapter Five, I present the two differences that this work focuses on. In the first part of the chapter, I present the narrative inquiry into Attention Deficit and Hyperactivity Disorder that I undertook with the collaboration of five mothers. Their stories are intertwined with supporting academic literature. In the second part of the chapter, I present Klinefelter Syndrome, and a popular literature overview, which demonstrates the common narrative about people with

Variations of Sexual Development. In this second part, I also relate the story about the day that my son was diagnosed with Klinefelter Syndrome, and a reflection on the interactions, which I had with the two medical doctors concerned, with my PhD advisor, Sheila McNamee.

In Chapter Six, I present the ongoing project of identity construction with an autoethnographic account of my different voices associated with motherhood. I intertwine the accounts with supporting academic literature.

In Chapter Seven, I reflect upon this body of work and the making of this dissertation. I write about the possibilities that are available by writing this dissertation, and by focusing on how I can imagine that it could be otherwise.

In Chapter Eight, I present two different qualitative, evaluative criteria that could be applied to this dissertation, and the possibilities of future inquiries.

1.9. Conclusion

This inquiry has to some extent allowed me to explore my story and my experiences. It has become a “pragmatic truth” (McNamee, 1989: 99 and 106), a form of storytelling, which reveals my logic or moral order (McNamee, 2008) as a mother. But as I write this pragmatic truth, it changes. It metamorphoses, as does my angry voice, and becomes one version of the story whilst many other versions might be available. This way of storytelling fits comfortably with me as it allows me to make sense of my preferred way of mothering or engaging in motherhood. One of the outcomes of my inquiry is that I find myself transformed into a version of myself that I prefer.

Chapter 2: Social construction

2.1. Social construction as a philosophical stance

In the first part of this chapter I present social construction as a philosophical stance, and outline my understanding of social constructionist premises that underpin the inquiry that I have chosen to undertake. My inquiry, and the research form that it takes, is very different from traditional scientific research, and I hope that my way of explaining the premises is both clear and helpful to your understanding. In the second part of this chapter I present identity as a social construction. I argue for the acceptance of identity as a way of describing and storying ourselves which I consider an ongoing project. From this point of view we are continuously restorying ourselves, sometimes in reaction to being categorised in one way or another. This notion of identity is important in this dissertation as I will in later chapters demonstrate how motherhood can be considered an identity that is constructed within the social environment and our relationships.

2.1.1. Introduction

Social construction invites us to reconsider the ways in which we think about human life and relationships. The opportunities to reconsider often transform what we “know” about human life and relationships. Gergen and Gergen (2003:15) write, “Social constructionist inquiry is principally concerned with explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live.” It aims to look at both the metatheory and the practices. Gergen¹ writes that social construction functions on the levels of both metatheory, or a general orientation to life, and specific or local sets of constructed ideas and practices. He writes, “What does this mean? At the level of metatheory, one simply views all theories and practices as social constructions. This is to recognize that all our languages, customs and traditions are outcomes of people’s relations.” This description frames how I want to approach my inquiry into the social construction of identity, and in particular the construction of my identity as a mother within the available discourses related to motherhood. This chapter summarizes my understanding of social construction.

2.1.2 A philosophical stance – a general orientation to life

Social construction is more of a philosophical stance than a method (McNamee, private conversation, 2009). Philosophy, the “love of wisdom”, is a way of

¹ The Taos Institute newsletter dated October 2011 retrieved from the Taos website www.taosinstitute.org

addressing the general, fundamental problems, such as reality, existence, knowledge, reason, mind and values, through an analytical and critical approach, using rational argument².

Social construction is also a philosophy of science as it looks at the assumptions that underpin the findings of scientific communities. In a modernist world, scientists and experts have created our understanding of human life in their various discourses. Generally speaking, they see themselves as discovering the world, rather than labelling what they can see in the manner they see it. This analysis of assumptions presents a challenge to modernist science. Modernism refers not just to the period of time starting with the Enlightenment, but with the general hope and faith placed in the scientific method to provide us with universal laws based on reason (Crotty, 2010: 185). McNamee and Hosking (2012:19-20) draw on Woolgar's notion of "Received View of Science" and outline the assumptions that are taken for granted within the modernist paradigm. The scientific method, within this paradigm, is also called the positivist viewpoint. The positivist viewpoint "argues that nature will reveal its secrets in an unambiguous way to those who accurately follow the methods of natural science" (Gergen, Cisneros-Puebla & Faux, 2008).

2.1.3. A challenge to modernist science

The modernist tradition of science aims to create universal "truths," including concepts or categories by which everything can be neatly described and explained (Nersessian, 2008; Lakoff, 1987). To the constructionist, these truths are seen as social artifacts, more the product of a historically situated interchange that prevails through the "vagaries of social process" (Espin and Gawelek, 1992: 1985) rather than through their empirical validity. Moreover, this type of modernist language creates experts, those people who position themselves as being the detainers of the truth, and drown out the voices of those who are otherwise experienced. Social construction is considered post-modern because it acknowledges that science is only one language amongst others; scientists do not hold the only truth, or the only reality. Gergen has written about the purpose of science as being "dedicated to illuminating the [...] truth," but reminds us that this truth is "according to [science's] assumptions, forms of reasoning, and internal system of values" (Gergen, Cisneros-Puebla & Faux, 2008).

However, these modernist discourses have become embedded in the dominant discourses in our society. Modern power is maintained through the sustaining of these discourses, i.e. they empower some and disempower others. An example of modern power within the discourses of motherhood is Rousseau's (1762)

² Wikipedia's definition, retrieved from www.wikipedia.org/philosophy, on June 4 2012,

discourse about natural motherhood. Malacrida (2003:37) writes that Rousseau's book, *Emile*, ushered in a long tradition of expert advice on mothering, establishing a discourse of good mothering as a natural state, one in which the "ideal woman would be the one who came closest to the animal" which naturally provided nutrients and care to its young (Badinter, 1981: 155-6)."

Social construction invites us to deconstruct the language games and discourses that are dominant in particular contexts at particular moments in history. The following section offers possibilities on how we may go about this practice.

2.1.4. Language games and deconstruction of discourses

Language is not seen as representative of a reality, but rather constitutive, in that it creates the ways in which we perceive, understand and engage with others in our lives. For example, when we talk about motherhood we are not just observing and remarking on what exists. We are focusing on certain happenings, which we make meaningful. We may incite mothers to behave or relate in certain ways to their children that we value in certain instances. These instances are what Wittgenstein called, "language games" (2009: 15e). They can be considered patterns or ritualized ways of talking. The way we address another person, or an audience, through our talk is a relational activity. Therefore talk, or communication, is not simply reduced to the transmission of meaning from one person to another (Pearce, 2007). We could say that within a language game, such as "giving advice," in which a doctor gives advice to a mother on how to deal with her child, there are ritualized ways of talking, listening, taking turns, asking questions or not asking questions, and so on. Within that engagement of doctor and mother, both are rehearsing and repeating the "normative expectations" that maintain "an intelligible whole" (Shotter in McNamee and Shotter, 2004). If one of the two people were to act differently, their actions may "puzzle, bewilder or disorient" the other person. That is not to say that both experience the ritual as satisfying or helpful.

As an example, when a mother consults a doctor about her child, the doctor may be acting from the premise that his or her words of advice are helpful to the mother. However, it may be that the mother experiences differently. If the advice is different from what she has been doing, it could imply that what she has been doing so far is of little value. She may then feel disempowered. On the other hand, it is possible that the mother sees the advice as a different way of doing something that she couldn't do until this moment, and the doctor's advice opens up the possibility of achievement. She may then feel empowered. However, it may be that a doctor does not always find out whether his or her advice is well accepted. There are, within the doctor-patient relationship, few occasions for direct feedback and open negotiation about the ways of relating. In my experience, there were few conversations between a doctor and myself where we ended our ritual of giving and receiving advice to reflect together on the usefulness of the conversation. I experience this reflection very often when working as a coach in organizations, when I ask the person I am coaching if the

conversation was helpful, and what specifically was helpful. I remind myself that this practice of reflection in coaching is also a language game, and one that has the potential of becoming a ritual, void of meaning, if done without purposeful intention of attending to the relationship.

In our example of the mother and doctor talking together, we are reminded that they are also members of other communities. The doctors are part of the community of doctors. The mothers are part of the community of mothers. Within these communities they may find themselves creating and maintaining the discourse about the other community. The doctor will draw on the discourses, the bodies of knowledge, about illnesses and diseases to give the mother advice. For example, in many European countries, the medical discourse about children with sexual chromosomic differences has encouraged many doctors to advise pregnant women to abort these fetuses. The term used in French to describe the abortion is different from the common term. When a doctor recommends such an abortion, it is a medical, or therapeutic, termination of pregnancy (*une interruption médicale, ou thérapeutique, de grossesse*). If a woman elects to abort her child without such a recommendation, the act is generally known as a voluntary termination of pregnancy (*une interruption volontaire de grossesse*). The doctor's advice or recommendation is associated with his or her status, medical knowledge and former experiences. The receiving mother's knowledge and experience may be limited, and she may place her faith in the doctor and follow his or her advice. When she tells another member of her community of mothers that she is carrying a child with a sex chromosomic difference, that member may well ask her what the doctor's advice is. By referring to the doctor, the mothers remind themselves of the medical discourse.

When we create or maintain a discourse about another group of people it can be considered that we treat them like "serviceable others," like objects whose actions and characteristics we observe, study and interpret without their involvement. Sampson (2008:4) describes the white male who has determined the standards for so many groups in discourses that "service his own interests, desires and fears." It is perhaps the fear of being defined, without being included in the making of that definition, which incites me to write in a somewhat reactive style in this dissertation. By writing about my experiences of professionals, I can be experienced as creating a discourse about professionals. It can also be seen as a construction on my experiences – as an autoethnography, a term which I will explain in more detail in Chapter Three – and a desire to have my voice and the voices of other mothers heard by the professionals.

Weingarten (1998) uses Scott's (1990) definition of discourse as "a historically, socially, and institutionally specific structure of statements, terms, categories and beliefs which are embedded in institutions, social relationships, and texts." This definition reveals the extent of the potential strength of a discourse. A

discourse is often the result of many years and many contributions by many people, all of whom may be united to argue its case, or defend its cause. When a discourse silences others, it may be excluding other virtues, values or possibilities. Gergen (in Gergen, Cisneros-Puebla & Faux, 2008) argues that there must be something outside the discourse worth attending to, and that the social constructionist must ask, “what then are you eradicating? Who has lost the right to voice? Who is silenced?” Lupton (1994: 55) writes, when we focus our attention on discourse we can ask the following questions, “In whose interests is the discourse operating? What (and whose) values, beliefs, and concepts are espoused, and what others are neglected? What pre-established knowledge or belief systems are drawn upon to create meaning? What types of social differences are established or perpetuated?” By seeing a discourse, and its related practices, in the service of another person, as a construction, something that was invented by people is to imagine how it could be otherwise. I am reassured by the idea that the discourse came to be within a community and that it was constructed by the community for a purpose, which was valid and meaningful at that given point in time. I can understand that practices and discourses that are not valid or meaningful for me could be considered important and relevant for others. This allows me to remain curious about how discourses came to be. Social construction also draws on Derrida’s (1982) deconstructionist philosophy, which refers to the taking apart of what has already been implicitly put together in a text. By deconstructing a text, we disassemble the authority of the text to suggest many meanings. This opening up of possibilities within texts allows us to engage in an ongoing conversation (Powell, 1997).

White (2007: 268) draws on Foucault’s (1973) notion of modern power, sometimes referred to as power/knowledge, where social control is established through the construction of standards or expectations by others. In Narrative Therapy Whites invites people to understand the context of modern power relations in which they are involved, in order to see what possibilities are open to them. Burr (2003) invites us to examine discourses for their political implications. She writes, “The popular representation of the good mother as one who spends time with her children when they are young and who sacrifices her own needs to theirs helps to keep women out of full-time employment and ensures their economic dependency on men” (ibid: 123). She reminds us that there are positions within different and competing discourses that are less personally damaging, and that our task is to find ways of resisting being positioned in them, and to find more beneficial discourses.

Within the discourses that are available to us, we may take up ‘subject positions’ as per Althusser’s (1971) idea of interpellation in that we find ourselves spontaneously fitting in with an ideological position, hovering on that edge of already or always becoming willingly situated. We may find ourselves positioned as Other, thereby possibly seeing ourselves as having little choice (agency) perhaps with little possibility of changing what we see as the *status*

quo that has been decided by others. In doing so, we continue to maintain the discourses even if we do not enjoy our subject positions. In the second part of this chapter, under Point 2.12., I will talk more about identity and the concept of ‘internalizing’ subject positions of discourses. When we internalize a subject position or a discourse, we find that we can maintain the discourse by making the same claims. For example, mothers who suffer from criticism admit to criticizing other mothers for not complying with societal expectations. Perhaps there is an unspoken belief that if we would adhere to these dominant discourses, that our lives would be easier. It seems to follow that if we don’t have easier lives, then we have not applied the discourses’ prescriptions. We all maintain these discourses within our ongoing social or relational interactions, and through these we narrate our identity, or our sense of self (Bruner, 1991).

What we commonly call interactions or situations, McNamee (2008) calls coordinations. Each coordination creates rituals or patterns of behavior. For example, when a mother goes to see a teacher she and the teacher find themselves performing a ritual in their exchanges about the mother’s child who is also the teacher’s pupil. Our ritualized patterns of interaction, over time, generate a sense of standards and expectations of both mothers and teachers. Teachers are “allowed” or expected to say certain things in a certain way. Mothers are expected to behave in a certain way. These standards and expectations, in turn, contribute to the construction of entire moral orders – that is, belief systems that guide our future interactions. These moral orders take the form of statements such as, “This is the right way for us to continue together.”

This reminds me of having a heated exchange with Edward’s teacher, Ms. S., about Edward’s homework when he was about six years old. I went through many different educational systems growing up in England, United States and German-speaking Switzerland. I had no knowledge about schools in Geneva. Perhaps I would have needed a course for beginners on the Swiss-French educational system when Edward started school. For me, it seemed silly that children should have homework in primary school. The exchange between Ms. S. and me was heated and uncomfortable for both of us as we negotiated whether parents should be expected to do homework with their children. Additionally what was at stake was whose authority was to be followed. I certainly did not follow the common ritual of behaviours, nor did I fit the expectations that teachers had of mothers. No wonder we were both so morally outraged with each other.

McNamee’s model of coordinations allows to us look at the different aspects of a situation or an interaction.

Social construction invites us to question the assumptions as we unpack them, and ultimately to choose what things we value, what we believe. Tal (1996: 5) writes, “Unlike the most playful of the deconstructionists, we do not seek to

prove that there is, finally, no solid place to stand. We have moved beyond the discovery of the reductive power of the question ‘why?’” Tal argues that we strive to find a place of knowing what we value and believe in, and that “cultural critics seek to establish a mode of discourse in which each person can first uncover and acknowledge his or her beliefs, and then test them, compare them to the beliefs of others, understand their implications, and modify them to reflect a changing understanding of the world. Our end goal is a community where difference is not only accepted but cherished because it provides us with new frames of reference and new ways of understanding ourselves.” McNamee (2008) expresses the same hope through the use of dialogue, which she describes through drawing on Bakhtin’s (1981) understanding, as “ a responsive, multi-voiced activity, and as such is not limited to self-interest, psychological or relational improvement, or to crafting cooperative, conflict-free ways of living.” McNamee writes, “dialogue is a process of holding firmly to one’s position while maintaining a curiosity and respect for another’s very different position” (McNamee, 2008).

2.1.5. The possibilities of alternative stories

The attraction of social construction, for me, is to be able to consider the notion of multiplicity of perspectives, truths or theories. Coming from the study of psychology, I have been immersed in the debates surrounding the scientific basis of psychology in experimental, cognitive, behavioural and organizational psychology. This discourse of scientific psychology is seductive in that it seems to hold hope for the identification and categorization of psychological phenomena, which will lead to the improvement of people’s lives, or as some may call it, mental health.

However, the consequences of psychological theories show that beyond identification and categorization, there is a focus on prediction and control of people’s lives. For example, when we ask for help to relieve our psychological suffering, we find ourselves being told why it is that we are the way we are. In order to be “cured,” we have to immerse ourselves in the theories that are proffered to us. There is a discourse that says when we are told why we are the way we are, we will find other ways to be.

However, most psychological theories are stories or metaphors about how we function. Many are based on structuralist assumptions that there is a deep, inner, underlying structure to our minds, our thoughts and our practices. Structuralism tends to reify concepts, to assume that they are real things, for example, our memory is supposedly divided into working memory, autobiographical memory and semantic memory. Amongst structuralist assumptions is the notion that internal structures or states determine people’s actions and behaviours. If these internal structures are considered real things, there seems to be a tendency that to believe that what is real cannot be changed. If a psychological pathology is real, and is located within a person, then what are the chances of changing, of being cured, or being otherwise? Will the person who tells me what my

pathology is, who is convinced that this pathology is real and inherent, be able to help me see myself differently? Will he or she be able to see me differently?

It would seem to me that psychological theories are conflated into discourses which, in turn, find themselves within the coordinations of everyday life. To read Bettelheim's (1987) description of the dyadic, or mutually influential, relationship between the mother and child is to discover a structuralist and prescriptive account of how the mother, the primary care-taker, must behave in order to allow the child's inherent nature develop. McNamee (2004) points out that we can choose the theories that are useful to inform our practices. To define what I mean by useful, I draw on Burr (2003: 123) who talks of finding discourses that are "less personally damaging" or "beneficial" to us, that allow us to position ourselves differently. Personally I find some of Bettelheim's advice (1987: 242) offensive as it positions me as subservient, or in opposition to my child. I am now free to pick another theory, with other assumptions, that are more useful. This is what I have tried to do in this dissertation. McNamee (2004) recommends that I do not oppose the others for the sake of opposition, but that I state my reasons and describe my experience of the consequences of those I do not wish to take part in. This is how I have negotiated my identity within the theories of social sciences through adopting the philosophical stance of social construction.

This philosophical stance allows me to read modernist, structuralist, psychological accounts and consider them to be part of the multiplicity of texts. It allows me to read accounts as being one possible version of an experience, such as guilt and shame, which I discuss in Chapter Four, under Point 4.7. It also begs me to remain open to considering other versions. It reminds me that to reconsider the essentialist perspective that a condition is unalterable, internal and enduring. Doing this allows me to consider a mother who is momentarily confused or sad or frustrated at not being able to deal with the situations she finds herself in with her child, as being that way at a certain point in time, and not enduringly depressed.

As you read my dissertation, I hope that you will come to see why a social constructionist reading of my experience is so important to me and to other mothers, who have been described in pejorative terms.

2.1.6. The practices of "going on together"

In the world of social construction à la Gergen, we remain attached to the Wittgensteinian notion of "*How do we go on together?*" This notion points to the relational act of doing something together, forming new possibilities, and opening up new potentials for action. Gergen's work (Gergen, Puebla-Cisneros & Faux, 2008; Gergen, 2009) on 'relational theory' focuses on relational coordination as a way forward in constructing possibilities, as well as developing new forms of inquiry and methods of research, which he calls the 'reconstructive phase' of social construction. This invites me to write an

autoethnographic account of my experience and inquire into other mothers' experience in a way that places an emphasis on their understandings, their ways of making meaning, without reducing it to terms that perhaps would not reflect their words. This qualitative form of research also focuses on dialoguing in such a way that the participants, or co-researchers, feel respected and valued for their experience. There are some who have written about the therapeutic aspect of interviews, and found that interviews were considered more therapeutic than counselling (Gale, 1992). In Chapter Five, I recount the experiences of the mothers in my narrative inquiry, as well as their reactions to telling their stories. I also recount in Chapter 7, under Point 7.5., how one of them talked in positive terms about the interview. As we continue together, the validation and valuing of our co-researchers (Epston, 1999) are so important in creating shared knowledge.

Pearce (2007: 53) formulates this notion of "going on together" in his "communicative perspective on social worlds" by asking us to reflect on our practices with the four following questions: "What are we making together? How are we making it? What are we becoming as we make this? How can we make better social worlds?" Our traditional focus on quantitative research can seem to treat our participants as "serviceable others" (Sampson, 2008). The statistics sometimes have the weight of the majority, and incite many a decision-maker to implement changes. However, many of us have filled in a questionnaire and wished for a place to write our comments, and to share how we make sense of what is being inquired about. We are treated anonymously, not out just out of respect for ourselves, but in order for the researcher to be held accountable for the way we are positioned in the research. Making better worlds requires different involvement of the people involved in our research.

It may also require that we not only look at past and present practices, but that we inquire as to what could be done in the future. Smart (2007) writes that the focus on the past and the present in research is to anchor the old ways of doing things, and avoids imagining the future. Our research should not only ask about what has been, but also what could be. May (2005) writes that we should draw on Deleuze's questions "How might one live?" (ibid: 7), and find ourselves in "new forms of life" (ibid:15).

Appreciative Inquiry (Cooperrider, 1987) invites us to look at what has worked best in the past and present, in order to anchor it and make it available for further, richer development. This is something that I endeavoured to do in my narrative inquiry.

McNamee (2004) proposes that social construction is a practical theory, "a relational practice, a way of making sense and engaging with the world that invites others into dialogue." How do we start? I would suggest that we start to listen to those whose voices have not been heard, to allow them to speak.

Inviting others into dialogue could be done in many ways, not all of them are used in research. Today's age of the internet has allowed multiple voices to express themselves and to be heard. In Switzerland, there is political recognition of the usefulness of support groups for people with chronic illnesses. Being heard and sharing experiences creates a sense of collective meaningfulness (Herzog-Diem and Huber, 2008:13). Mental health service users and survivors (Rose, 2008) have started doing research of their own. "Hearing Voices" is a group that has come to claim that hearing voices is not necessarily a pathology that requires the medical focus on symptom reduction. The reliance on the expert is being diminished, as the "experts through experience" (Herzog-Diem and Huber, 2008:12) start to be heard and affirm their form of knowledge. As Foucault (1972) pointed out, "In the most recent upheaval the intellectual discovered that the masses no longer need him to gain knowledge: they know perfectly well, without illusion; they know far better than he and they are certainly capable of expressing themselves." My inquiry reaches into the experience of mothers who are experts through their embodied and relational experiences of motherhood. I ask them to express their narratives, tell their stories, so we might seek together other ways we could propose for mother-professional interaction.

2.1.7. Story-telling and meaning making

Pennebaker and Seagal (1999:1243) write, "The guiding assumption [...] is that the act of constructing stories is a natural human process that helps individuals to understand their experiences and themselves."

To what extent is story-telling a *natural human process*? I would question, first of all, the assumption that we have natural human processes. I would also ask, when we say a human process is natural, what does that statement do? To state that something is *natural*, according to the Merriam-Webster online dictionary³ means to infer that it is "right", "legitimate", or "inborn", "bestowed upon an individual by nature." If something is deemed natural or normal in our society, it usually refers to it having become habitual or typical. I would therefore propose that we have culturally legitimate, relational processes that we call storytelling, which are habitual, and that we have come to appreciate certain forms of stories. Gergen and Gergen (1988) tell us that, in our culture, a story must have a goal, and that the important events of one's life should be constructed, in chronological order, to show how one went about meeting that goal. From psychology, anthropology and ethnology, the story of storytelling has flooded the professional and academic world of organizational psychology. Ibarra and Lineback (2004) write, "All of us construct narratives about ourselves – where we've come from, where we're going. The kinds of stories we tell make an enormous difference in how we cope with change."

³ Retrieved from www.merriam-webster.com on April 28, 2012

Pennebaker and Seagal (1999) go on to say that constructing a story allows us “to organize and remember events in a coherent fashion while integrating thoughts and feelings. In essence, this gives individuals a sense of predictability and control over their lives.”

We are told by Burton and King (2004), “the importance of creating a coherent narrative and gaining understanding of experience has come to be viewed as a crucial mechanism” (151). I ask myself, what it is crucial for? For explaining ourselves, for presenting ourselves as coherent, predictable and in control? We must portray ourselves in a particular manner which would be considered coherent. Without this form, our voices may not be heard. With the rise of psychology in our everyday lives, the quest for meaning making is no longer for those who, in suffering, seek out the psychotherapist, but for all of us. It has become the dominant cultural discourse. It has been created by us, we are now beholden to it, to the extent that we take it for granted and label it “natural.”

Narrating my story became a way of making meaning out of all my experiences; it was “the curious process by which people construct what we call ‘a self’ and ‘a life’”(Bruner, 1991). It became a study in the process of social construction of identity, my self as a mother.

According to Bruner (1991), a narrative must not only have the qualities that provide coherence that Gergen and Gergen (1988) mentioned, but “it must also contain something that endows it with *exceptionality*.” A story must upset our cultural expectations through some violation, some surprise, but it must also provide some form of comprehensibility, and in that way it becomes “tell-able”. One is allowed to tell a story about an exceptional life, where there are difficulties or complexities that require demystification. My goal to be a mother was not made explicit. I cannot say that I set out on a quest and encountered various obstacles. Later in my experience of being a mother I told a friend, that if there was such a thing as Heaven, as portrayed by the Catholic Church as I understood it, when I got to the Pearly Gates and St. Peter asked me, why I should be admitted, I would tell him because I had tried my hardest to be a “good enough mother.” He will, hopefully, have read my story by then and come to a decision about whether my story was exceptional and whether I was a “good enough” to be rewarded.

I have talked in the conclusion to Chapter One about my story being a chaotic narrative (Frank, 1995), and a formulation of a “pragmatic truth” which shows my logic and moral order (McNamee, 1989). In Chapter Four, under the heading of “Writing,” I describe this experience of writing my story, which reflected Pennebaker and Seagal’s (1999) notion that writing allows one to structure and give meaning to events that have happened. Although the writing may remind us of emotionally evocative events, the feelings become more manageable, and the voices subside. Sophie Calle in her book *Douleur exquise* (Exquisite Pain, 2003) writes about her experiences during the ninety days preceding a painful event, as if to describe her naivety, her lack of

consciousness or reflection about what could happen to her. After the event, she wrote about it for another ninety days after the event. She juxtaposes her description of this one story with other people's stories about their most painful life experience. As the days go by, her accounts change. She incorporates parts that she hadn't told before. Her story becomes shorter and shorter, as if her pain and the need to recount her pain are reduced. She was re-storying her experience through the narration. Social construction reminds us that stories evolve and change, that a meaning is never fixed forever. My story continues to change each time I think about it. We can see, therefore, that if meaning is fluid, there can never be one truth.

2.1.8. Restorying

People describe and define themselves through stories (White, 2005). We pick and choose which stories to tell depending on how we want to present ourselves to another person. White (2005: 10) says that when people go to see a therapist, they tell their stories by linking events together to tell a persuasive storyline. They persuade themselves perhaps more than they persuade others.

Restorying or re-authoring is about finding moments in time, what Michael White calls "unique outcomes," that provide a different insight, a different perspective, and start a process of linking similar events with similar meanings to create new meaning, to create new identity, a process embedded within social constructionist thinking.

Re-authoring conversations re-invigorate people's efforts to understand what it is that is happening in their lives, what it is that has happened, how it has happened, and what it all means. (White, 2005:10) This is not about discovering a reality, but allowing us to make sense of our lives through different ways.

There is no causal explanation of "why?" something has happened. We can recount what has happened and how it happened. Each time we try to answer the question, "why?" we embark on another story (McNamee, 2010, personal conversation).

This notion of "re-authoring", of re-creating a different meaning in life is one that we find difficult in our Western way of thinking. We see ourselves to be coherent, separate individuals. Gergen (2009: 135) says that most mental suffering is caused today by the societal requirement to present ourselves as consistently coherent. We are supposed to have an essence, a true self within us. When so much of our energy has been invested in maintaining a particular story, it is hard to change that story, to say good-bye to an attachment. A recent article on the website of the Guardian newspaper highlights stories that people have held on to for many years; an Australian nurse, Bronnie Ware, who spent several years working in palliative care, caring for patients in the last 12 weeks of their lives. "When questioned about any regrets they had or anything they would do differently," she says, "common themes surfaced again and again." Of the five regrets, number 5 is "I wish that I had let myself be happier." "Ware

writes: This is a surprisingly common one. Many did not realise until the end that happiness is a choice. They had stayed stuck in old patterns and habits. The so-called 'comfort' of familiarity overflowed into their emotions, as well as their physical lives. Fear of change had them pretending to others, and to their selves, that they were content, when deep within, they longed to laugh properly and have silliness in their life again." (Steiner, 2012)

It is easier said than done, to 'choose' to see oneself differently, to position oneself in a different light, to let go of those preferred performances that we have enacted together for so long. One of the ways that allows us to see ourselves differently is through the practice of re-membling, another practice rooted within social construction.

2.1.9. Re-membling

The practice of re-membling (White and Epston, 1990:191) used in Narrative Therapy is based on Barbara Myerhoff's (1982) idea that everyone has a "club of life", made up of significant others who have been part of one's life. In her study, she found that those who had lost a close person preserved the stories and memories of their loved ones, while adjusting to their physical absence. White (2007: 13) writes, "Re-membling, as defined by Myerhoff, contributes to the development of a 'multivoiced' sense of identity and facilitates activity in making sense of one's existence and achieving a sense of coherence through the 'ordering' of life. It is through re-membling that 'life is given a shape that extends back in the past and forward into the future' (Myerhoff, 1982: 111)." David Epston (1990: 83) has described the use of this process in helping people to re-story their lives. He asks the people he helps to find those people within his or her circle of friends, acquaintances, teachers, and others, who know that they can be different, that they can act in ways they are generally not perceived to be capable of. It seems that when we know that there is at least one person who can see us differently, the potential of developing that difference increases. As Bateson said, "it is the difference that makes the difference" (Bateson, 1972).

The writing of my story and this dissertation allowed me to re-member my "club of life" with those people who offered me support during the years of difficulty. I also found that there were many reminders of how Edward was experienced, which were painful and not in accordance with how I experience him today. I have told you in the introduction how I see him today. I talk more of the method of re-membling in Chapter Four. In Appendix B you will find these stories of Edward.

2.1.10. Social construction is also a construction

The stance of social construction is criticised for being relativist, taking a position of 'anything goes' as long as we can dismantle the experts' discourse, render visible the power/knowledge within it, and reveal the assumptions behind it. The process of standing back and looking critically at a discourse can

only happen within another discourse, from another subject position. So even in social construction, there is no neutral observer, no ‘god’s eye’ of justice and righteousness that says, “yes, you’ve got it right”. As I have gained my knowledge of social construction, and as I have started to look at my story, and other subjects in my life, I have either upset myself or others by seeing beliefs as part of a discourse and not “truths”, to the extent that my exasperated daughter, Beatrix, states the obvious back to me, “social construction is also a social construction.” Gergen reminds us that social construction has no claim to truth, rationality or value over any other way of looking at things, and that we should retain both curiosity about others’ views and a “certain humility regarding one’s own views” (Gergen, Cisneros-Puebla & Faux, 2008). This way of being in the world allows us to search for multiplicity of perspectives and to select those that we value, that resonate in our lives, that are useful in making sense of our lives.

2.1.11. Conclusion

In this chapter, I put forward the premises of social construction and the different constructs that I find are useful in allowing me to be able to look at my experience. These are the resources that informed my choice of methodology and assisted me in developing my inquiry and my reflexivity. Before starting this inquiry I would have situated my work within critical social psychology (Wetherell in Sapsford, 2001: 11) for a number of reasons. The primary reason being that it deals with the development of a sense of self within relationships built up over a period of time within a local, historical context. This invites me to move towards sociological social psychology in that my inquiry leans towards the idea of how social life creates our internal life of the life-world of a person, as Husserl (1931) described it, and avoids forms of psychology which consider the social context “an additional variable which modifies individual psychology but is not formative or constitutive” (ibid: 16). Social construction allows me to go further than simply seeing the impact the social world has upon us, and to focus, instead, on how we are created in our social interactions. The latter way of considering how we go about making sense of our lives suits me more profoundly. It is within this mode of sense-making that I will now address the notion of identity.

2.2. Identity as a social construction

2.2.1. Introduction

In this section on the notion of identity, I discuss how social construction describes the notion of identity or self. I draw on other schools of thought, outside modernist psychology, to show how widespread this notion is becoming, and the forms it takes. I also discuss the ways in which we become “polyphonic” or multiple beings (Gergen, 2009), through the ongoing project of identity construction. Furthermore, I argue that the notion of multiple beings is not popular because it is often linked to the psychiatric pathology of

schizophrenia. In other words, I hope that I have answered the following questions in this chapter:

- How is it that I find myself composed of multiple voices?
- I have told you about my desire to find out how my voice of “Edward’s mother” developed. How did she develop?
- I have told you about my “guilty” voice and my “angry” voice? How are these voices part of my personality?
- How can I find a notion that encompasses these sometimes very different experiences of myself? How can all of these voices sit within me?
- Can I be sane with these multiple voices?

2.2.2. Identity is a social or relational achievement

Having introduced the term of subject positions in Point 2.4., I continue to use this term alternating with self and identity in this section. As was stated before, subject positions within dominant cultural discourses invoke the idea that we create our identity through our relational interactions. Identity is considered a social or relational achievement in social construction. It is also considered an ongoing project, in that our identity can evolve over time or change significantly in suddenly different situations. McNamee describes identity as a “conversational resource – a way of talking that we quite often find useful in our attempts to coordinate with others [...] used by participants in their situated activities [which] implies that it is the discourse itself that becomes open to investigation as well as the relational context in which it emerges” (McNamee, 1996). Gergen talks of multi-being and of the “voice[s] one has acquired through relating with others” (2009: 141). Social construction therefore embraces the idea that we are created through relations, as well as the idea that we are multi-voiced, or have multiple selves. I use the term “self” in the sense of a “narrative social understanding (constructed reality) of self” (Anderson, 1997: 212), and for the sake of brevity.

Subject positions are not limited to our multiple roles in society (mother, daughter, sister, worker, colleague, employee, neighbour). They can also be functional positions that we take within a conversation (Winslade and Monk, 2008: 45). This concept of identity, constantly changing and becoming, goes against the psychological theories of individualism, personality and essentialism. In social construction we promote the idea that we do not have an inherent personality that develops independently of the culture and relations we have, but rather a fluid, changing ‘post-modernist’ identity. Anderson (1997: 211) writes, “Postmodernism challenges the idea of a single, fixed core self that we can reveal if we peel away the layers.”

The notion of multiple selves or sub-personalities has existed for a long time within various forms of psychodynamic practices, albeit with a structuralist perspective. Perhaps the most famous example is Freud’s model of the id, the

ego and the superego. John Rowan, author of *Subpersonalities; The people inside us* (1990) provides an historical overview of the notion of many selves, voices or sub-personalities. He mentions more than thirty prominent psychologists who have in some way described multiple beings, and used the notion of multiple parts in their structuralist approaches. Two such psychologists are Stone and Stone (1989) who talk of us being made up of many different selves, which develop from birth onwards within our relationships, and that we have “the potential to develop an infinite array of energy patterns or selves” (ibid: 13). According to the Stones’ approach Voice Dialogue, we develop within the relationships that we have with those around us. They write, “[i]n our developmental process we are rewarded for certain behaviours and punished for others; thus, some selves are strengthened and others are weakened. We learn our lessons well and consequently develop personalities. It is strange to think that a personality is actually a system of subpersonalities (selves)” (ibid: 14-15). From their experience, they describe a number of sub-personalities that develop in each person – again, an indicator of a modernist, structuralist approach – which include the Pleaser, the Pusher, the Protector/Controller, the Inner Critic. Manné’s (2006) approach does not focus on the “universal categories” but on using the words that a person put specific emphasis on, when talking about a problem. For example, if a person says, “I couldn’t give a damn about that project,” with an angry tone of voice and an accompanying gesture, then as a facilitator one would invite him or her to talk from “the voice that says it couldn’t give a damn about that project”. Rowan (1990:10) points out that it is not easily possible to “reify the subpersonalities” because they are “processes which are actually very fluid and in change.” It would seem that this is a coherent approach to change; we change through the development of potentials. I will talk more of the Stone’s approach Voice Dialogue in Chapter Four on methodology.

Stuart Hall in *Identity in Question* (1992) distinguishes between “three very different conceptions of identity: those of the (a) Enlightenment subject, (b) sociological subject, and (c) post-modern subject. The use of the term “subject” allows Hall to avoid using the term “self,” a modernist concept. The Enlightenment subject, the one I was most familiar with before embarking on this PhD program, is considered to be “centred, unified, individual, endowed with the capacities of reason, consciousness and action” (Hall, 1992). This notion includes the belief that we are born with an essential core, which unfolds during our life. This is what I, as a psychologist, would also call a “personality”. We in the Western world are very attached to this notion. This attachment is an example of how a technical, psychological term has become embedded in our way of talking. The psychological or medical discourse has permeated the discourse of the general public. We rehearse our belief in the existence of a personality in our daily talk about ourselves and others. We say, “He’s just like that ... it’s just his personality.” We invest thousands of dollars or Swiss Francs in trying to change individuals or organizations. Recently a young man said to me that some organizational psychologists had told him that it takes four years

to change a personality trait. He didn't like my reply, "if that is what they say, that is how long it will take them. It might take others a minute to change." When we, in a position of expert, prescribe the difficulty of changing our personality or the traits of our personality, then others will adhere to this discourse of difficulty.

2.2.3. The constructs and theories of self beyond modernist psychology

Navigating the different schools of thought and moving away from the constraints of modernist psychology, has increased my understanding of the notion of multiple selves and its appeal. Several authors (Hall, 1992; Stryker and Serpe, 1994; Charon, 1992; Sampson, 2008; Espin and Gawalek, 1992; Giddens, 1991; Burkitt, 1991; Burke and Stets, 2009; Harré, 2009; White, 2008; Foucault, 1972, 1973) contribute to the understanding of the socially created multiple voices of human beings. Along those terms I have already mentioned, there is Charon (1992) who talks of identity being part of the self-concept, and why it is that we have a need to define ourselves. He says, "We call social objects names, and this allows us to identify and classify them in a world of a multitude of social objects. So too do we give our selves a name. Our identities are simply the *names that we call our selves*" (1992: 82, italics original).

Harré et al (2009: 9) talks of "positions" considered "clusters of beliefs about how rights and duties are distributed in the course of an episode of personal interaction and the taken-for-granted practices in which most of these beliefs are concretely realized." This notion of position is one that goes beyond the implicit understandings that we may have, and demonstrates how a position is invested by discourse.

Espin and Gawalek (1992) write about the difficulty of seeing identity otherwise than socially constructed. They write, convincingly, "Feminist psychologists have consistently acknowledged the importance of the social, external structure of a woman's life in influencing the development of her sense of self. Feminist thinkers have recognized the importance of the individual experience of women and of the interplay of individual development and social context – an interaction which is so deeply entwined that it is fair to say there is no definition of an individual without a definition of her social context" (96).

2.2.4. The way in which we become how we are

The relational context and the process of insertion into that context is one that Elias (1994/2000) writes about in his epic book *The Civilizing Process*. Elias reports on how through generations, various thinkers and writers, like Nostradamus, have written about our social practices. I find it interesting to see how we can influence the perception of our personal practices through our language and over time. However, Elias's main argument, it seems to me, is to show how we become who we are through a socialization process whereby we are taught what is appropriate or inappropriate behaviour, movements, and

feelings. He questions how we can consider people separate from each other. He writes, “[S]ociety presents itself finally as a collection of individuals completely independent of each other, whose true essence is locked within them and completely independent of each other, whose true essence is locked within them and who therefore communicate only externally and from the surface” (ibid: 474). Elias tells us that to see individuals in this way “in absolute independence of each other is an artificial product” (ibid: 469), but one that has indeed convinced many. Elias replaces this notion with the “human being as an ‘open personality’ who possesses a greater or lesser degree of relative (but never absolute and total) autonomy vis-à-vis other people and who is, in fact, fundamentally orientated towards and dependent on other people throughout his or her life” (ibid: 481). If we can accept that we are interdependent, that we come to be who we are through social learning, education, socialization and “socially generated reciprocal needs,” then we exist only in figurations. Elias’ term, “figurations” is explained through the analogy of a dance with the “plurality of reciprocally orientated and dependent individuals” (ibid: 482).

Davies and Harré (in Harré and Van Langenhove, 1999) invite us to move away from social psychology’s dramaturgical model which focused on the notion of “role,” and to use the notions of “‘positioning’ and ‘subject position’ [which] allow us to think of ourselves as choosing subjects, locating ourselves in conversations according to those narrative forms with which we are familiar and bringing to those narratives our own subjective lived histories” (41). The authors use the example of the mother to demonstrate their point of view. They write, “The way we have been positioned and have positioned ourselves in relation to ‘mother’, the narratives that we have lived out in relation to particular mothers, mean that we bring to each new encounter with someone positioned as mother a personal history with its attendant emotions and beliefs *as well as* a knowledge of social structures.” (ibid: 42).

Hall (1992) says that we internalize the various identities, available within cultural discourses, with their meanings and values, “making them part of us,” which “aligns our subjective feelings with the objective places we occupy in the social and cultural world” (ibid: 276). There are, therefore, numerous authors and schools of thought upholding this notion of various identities being formed within the various discourses available to us. I have already discussed this in Chapter Two. However appealing this may be, there is also a threat to our accustomed comfort of seeing ourselves as coherent, consistent and separate. Hall’s description of the post-modern subject as “fragmented; composed, not of a single, but of several sometimes contradictory or unresolved, identities” (ibid: 277) may well seem disturbing. Hall does reassure us by saying that we may choose to identify with one of the multiple, possible identities and “construct a comforting story or ‘narrative of the self’” (ibid: 277). The notion of multiple selves adopted in self-theory within sociological social psychology invites us to envisage an organized structure which reassembles the multiple parts of self, or the multiple selves, in order to restore coherence. A person threatened by

feelings of fragmentation could be reassured by the idea that includes “the distinctiveness of differing selves or differing parts of an overall self” (Stryker and Serpe, 1994). There are others who subscribe to the view that although we may see ourselves as multiple, we prefer the comfort of a recognizable self that we can depend on. Tomm writes that he assumes that most people have a preference for internal coherence and consistency (Tomm in McNamee and Gergen, 1999: 131).

Social construction offers us a way of seeing how we are produced through our relationships. Gergen (2009) writes, “The person is essentially constituted, by a multiplicity of relationships. Some relations leave residues that are well practiced, while others leave little but whispers of possibility” (147). In every relationship there emerge potentials for being – dominant or submissive, churlish or kind, obedient or rebellious, and so on (ibid: 139). As we come into contact with our parents’ performances and their multiple selves, so we are open to the possibility of internalizing those. In one part of my story, I write to my mother, telling her how well I had organized Edward’s christening, and claiming proudly “to be my mother’s daughter.” By being like my mother, I mean that I know how to perform like my mother. This well-organized mother is one of my multiple selves, one that was learned from my mother and one that I appreciate enough to prefer. It seems a far easier and fluid process to learn, appreciate and become what has been offered to us within our circle of family and friends. We are who we are because of what came before us. We have inherited practices of thought, bodies of knowledge that have been passed down to us. Todd May (2006) describes Foucault’s way of writing an archeological history of who we are and the impact of our local history upon us. He writes, “It is because this particular history, with these particular events, led us to this place and not some other. The history that has brought us here could have been different. It did not have to take the paths it took. If it had, we ourselves would be different from who we are. [...] We did not have to be *this* rather than *that*, which means, among other things, that we do not have to continue to be this” (11). Foucault offers us the possibility, therefore, of not being limited to what we have become familiar with. Social construction offers us the idea of potential. I have written about how various schools of thought, to a greater or lesser extent, agree on the notion of multiple selves as opposed to the psychological notion of self. I have talked of how Gergen and Elias see the coming into being of these multiple selves. In this next section, I wish to talk about how these multiple selves appear in our lives, where they make themselves known.

2.2.5. Voices in my head, internal dialogue, and thinking

I have told you in Chapter 1 about my two voices that oppose each other on the subject of my son. I have told you that I was interested in inquiring into how the voice of “Edward’s Mother” came to be. Through social construction I understand that these voices have come about through various interactions or

situations in my life, in coordinations (McNamee, 2008) with others. I sometimes say these voices are “in my head.” I have told you before how my angry voice, which holds me responsible, continues, repetitive and monologic, until I pay attention to it. I draw on Ruesch and Bateson’s (2006) notion of internal monologue, one of the forms of intrapersonal communication. They described it as being the semi-constant internal monologue one has with oneself at a conscious or semi-conscious level. Others, such as Cooperrider (1987) have called it self talk, inner speech or internal dialogue. I have been intrigued for many years by the way some very elderly people talk to themselves as if they had forgotten the social injunction to keep their mouths shut while thinking. Lysack (2002) talks about the self as a “dynamic configuration of ‘inner’ conversations and discourses, internalized from ‘external’ conversation and interaction on an interpersonal level.” An example of this is Sidra Stone’s “inner patriarch,” a generalized male patriarchal discourse that, she claims, women have internalized and can easily uphold. As I have grown more comfortable with the idea of internal dialogue with my many possible selves, I find that they each have a particular tone of voice, a particular energy and language. It seems that they are indeed embodied performances in that they involve feelings, thoughts and movements. Marzari (in McNamee and Gergen, 1999) gives a wonderful example of his “multiplicity of voices” each of which “struggled to have its voice heard” in response to their invitation. These representations of different opinions, that we can easily hold, can be seen as multiple selves.

Both Piaget (1926) and Vygotsky (1978) observed small children who spent a lot of time talking to themselves. Piaget’s explanation was that children are egocentric and therefore do not understand that anybody could be listening to them. Vygotsky, on the other hand, was that the child was talking to herself, “the one person that really mattered” (Bentall, 2009: 178). Vygotsky’s work focused on how children seemed to acquire the capacity for verbal thought. Thought and language fuse when children communicate intrapersonally as if they were communicating with another person. As time goes on, children learn that talking to yourself should be done silently. Inner speech and social speech are thus separated (Bentall, 2009:178). Griffin, a symbolic interactionist, also describes “thinking as an inner conversation [...] We naturally talk to ourselves in order to sort out the meaning of a difficult conversation. But first we need language. Before we can think, we must be able to interact symbolically” (Griffin, 2006: 62).

Through the writing of my story, I have come to ‘see, hear and feel’ the multiple selves that occupy my being, and to some extent understand how they came to be, in which relationships these selves were constituted. I hope that the readers will see this as well, that you will enter into my world for a moment, and see how it came to be that ‘Edward’s mother’ emerged.

2.2.6. Giving up the notion of self as solo

What do we have to give up when we embrace the notion of multi-being? Bruner (1991) and Von Wright (2006) describe how the idea of having multiple selves and being the product of multiple relations goes against the grain of our Western commitment to the individual. Bruner (1991) argues that “it is probably a mistake to conceive of Self as solo, as locked up inside one person’s subjectivity, as hermetically sealed off (ibid: 76). Von Wright describes the two notions of ‘closed self’ and ‘open self’. The closed self is seen as “basically single and individual, as a cognitively autonomous subject” 2006: 160). Not only that, but as Eisenberg (1998: 99) tells us, we will suffer internal contradictions, should we not present ourselves as ‘unified’, and will need fixing. The theories supporting the idea of “open self” view us as “intersubjectively and socially constituted, and as basically plural” (Von Wright, 2006: 160). Bruner (1991) explains that, “Self seems also to be intersubjective or ‘distributed’ in the same way that one’s ‘knowledge’ is distributed beyond one’s head to include the friends and colleagues to whom one has access, the notes one has filed, the books one has on one’s shelves” (76). Perhaps it is with ‘tongue in cheek’ that Bruner remarks that the most enduring thing about ourselves is our “sense of commitment to a set of beliefs and values that we are unwilling (or unable) to submit to “radical” scrutiny” (76). Von Wright (2006) provides us with a plausible reason. “There is a common misconception that a notion of human subjectivity as social, based on plurality and intersubjectivity, wipes out the uniqueness and individuality” (161).

McNamee (1996) proposes that the “uniqueness” of our self, that we seem to be so attached to, could be considered as the “confluence of relational membership in various and multiple discursive communities or an individual’s meanings and experiences.”

It is not only this attachment to our uniqueness and individuality that psychology has instilled in us. It is also the fear of being considered irrational or schizophrenic by admitting that we have multiple selves.

2.2.7. Our fear of being labelled schizophrenic

« L'unique différence entre un fou et moi, c'est que moi je ne suis pas fou. » Salvador Dali, Journal d'un génie adolescent, 1994

For many people in the Western world, the idea of multiple selves is often linked to schizophrenia, a mental illness, involving “a fragmentation of thought, feeling, and action, [...] literally a schism within the phrenos, or mind, commonly misunderstood as ‘split personality’. The term ‘schizophrenia’ was coined by Bleuler in 1911” (Millon and Davis, 2000: 349). I would like to posit that we recognize our multiple selves from the internal dialogue we have with ourselves, which is a common, every day and taken-for-granted activity, and which differs very much from the auditory hallucinations or “hearing voices” symptoms of schizophrenia.

Bentall (2009) writes, “Inner speech is such a ubiquitous aspect of our mental life that, unless it is drawn to our attention, we rarely reflect on it. If you close your eyes and allow your mind to wander, you will discover an almost ceaseless inner chatter swirling within you. Using this inner voice, we comment to ourselves about what is happening to us, silently express our pleasure or dismay, plan what to do next, and censure ourselves whenever we make mistakes” *ibid.*: (178). This inner dialogue is different from the voices or auditory hallucinations described by those labelled schizophrenics. Bentall writes, in a “sample of 255 first-episode patients – most of whom met the DSM diagnostic criteria for schizophrenia – 69 per cent reported” (*ibid.*: 177) auditory hallucinations, that is, they heard voices that appeared to “be external to themselves” or when they were recognized as being internal, they were considered “alien” voices. Patients who suffer from these symptoms appear to find it difficult to differentiate between what they are thinking, i.e. what is going on internally, and what they are hearing, i.e. what sounds are coming from their environment.

Hornstein (2009) writes in *Agnes's Jacket*, that the “actual experience of voice hearing is surprisingly variable – for different people and even for the same person over time. But it's always qualitatively different from thinking aloud or talking to oneself. The voices are experienced as coming from other people, from birds or other animals, or from the TV, radio, or other objects. Many voice hearers say that the sounds come through their ears and are indistinguishable from the voices of people consensually agreed to be sitting in the same room. Others say the voices come from the space around their heads or from inside their skulls. ... But regardless of where they come from, they seem to come and go as if they have a life of their own” (*ibid.*: 35). Hornstein goes on to describe the “distinctive qualities of *voices* – as opposed to thoughts, inner dialogue, rumination, or dissociation... Voices give advice, threaten, swear, or inspire. They tell people to do things they may or may not want to do. Voices can be loud and articulate or barely audible... They can be accompanied by whisper, mutterings, or humming. They can incorporate strange noises – ticking or

clicking, bits of melody, or the far-off whoosh of a seashell held up to the ear. Voices can be male, female, or a mixture of both... They may sound as if they are coming from young children, or they may be robotic and machinelike. The voices may sound like someone the person knows now or in the past, or they can be totally unfamiliar. Some people hear the voices only in certain contexts; for others, they are a constant presence. Some voices speak the person's thoughts out loud, or two or three voices argue or provide a running commentary on the voice hearer's behaviour" (ibid: 35). She also writes about the different reactions that people have to these intrusive voices, and how "people who struggle to find an explanation for what's happening to them. The experience is just too unusual not to speculate on its cause" (ibid: 36). Are those that are labelled schizophrenics those who wanted to understand why they had such invasive voices in their head? There can also be momentary invasive voices or thoughts. Bentall (2009) writes, "It is known that traumatic experiences often provoke a continuous flood of intrusive, vivid and distressing thoughts (Brewin, 2003)" (Bentall, 2009: 180-1) in non-psychotic people. "Experimental studies show that these kinds of low cognitive thoughts that are unbidden and disturbing (they happen without intention or an act of will) are particularly difficult to recognize as self-generated, a problem that is often exacerbated by the individual's emotional reaction to them" (ibid: 181) That is, if you think you are going crazy because of all the thoughts swirling in your head, you are more likely to "engage in extreme attempts to suppress unwanted thoughts" which turns out for many to be "counter-productive, often leading to a rebound of the very experiences that are suppressed" (ibid: 181).

2.2.8. Conclusion

It would seem that we can have internal dialogue or conversations with the competing discourses in our heads, which we usually refer to as thinking, without being either schizophrenic or under extreme stress. If this is the case, then it would appear to be habitual for us to have multiple selves who present themselves to us in our internal dialogue. Like Marzari (in McNamee and Gergen, 1999) when we start to be attentive to the multitude of voices that clamour to have their voices heard – or the different and sometimes opposing ideas we can hold at the same time – we may come to an acceptance of the notion of multiple selves.

In this section on identity, I hope that I have created a plausible story about the utility and appeal of multiple being or relational selves (Gergen, 2009), and how our attachment to uniqueness and individuality, along with our fear of being labelled schizophrenic may long continue to be a stumbling block to the acceptance of multiple being.

Chapter 3: Methodology

In this chapter, I present the reiterative process that I went through from the moment of insertion into this project of inquiry and my initial interest, the formulation of a possible hypothesis, and the journey of my inquiry. Following this, I present my choice of methodologies: autoethnography, writing, voice dialogue, narrative inquiry, and re-membling. I address an initial question about ethics, one that I return to in Chapter 8 in more detail.

3.1. My moment of insertion

In my first workshop on the Taos-Tilburg program in June 2009, Dian-Marie Hosking and Sheila McNamee, my PhD advisor, invited us to inquire about a subject with which we have a “personal or ‘heart connection’”(ibid: 8). I have a personal connection with my children, Edward and Beatrix. In spite of my thirty years of professional engagement in Organizational Development, I felt myself more drawn to my then twenty-five years of maternal engagement. We were asked to discuss our focus of research in small groups. I was encouraged by my two workshop colleagues, Gerolf and Aileen, to elaborate on my question, “How did I come to develop a part of myself that I call ‘Edward’s mother’?” By going against the psychological notion of an inherent, autonomous, core self or personality that develops like a seed becoming a flower, social construction articulates the premise that our identity is an achievement of joint action. I will explain these notions more in this Chapter.

When Aileen asked me to talk more about “Edward’s mother,” I found myself assuming a physical posture, standing with my feet solidly on the ground, with a certain upwards tilt of my head, my shoulders upright, my arms bent from the elbow upwards, and my hands slightly clenched. This bodily stance has become familiar to me as I have paid more attention to it over the past few years, and it is not only in regard to my children that I solicit the intervention of “Edward’s mother.” She is sometimes a useful ally in my professional life although it has been a rare occurrence to have to defend myself, or my children, to the extent that I have in my non-professional life. My eyes seem to squint while I focus on the person in front of me, as I give my full attention to what is being said to me. I am on the defensive, ready to defend. I am, perhaps, selectively listening for what I could identify as an attack, so as to be ready to counter-attack. This part of me, this voice of mine, is a part of a performance enacted in a variety of scenarios that has become part of my repertoire as a mother. Here lies the passion of my inquiry with all its constraints and potentiations.

3.2. Developing my field of inquiry

From this initial moment of choosing to look at “How did I become ‘Edward’s mother?’” this way of inquiring could have led me to focus on my individual story, separate from the social context in which I lived. This may have the tinge of a constructivist approach, which I had progressively become uncomfortable with. When I speak of constructivism, I mean a more individualistic way of going about making sense of particular meanings pertaining to mothers, and/or motherhood, which can be from the social interactions that I experienced. Individualism refers to all the practices that consider individuals as islands unto themselves. This notion of individualism leads us to be held uniquely responsible for what it is that we do and say.

Would being able to look at our relational practices of motherhood allow a different reading, a different kind of sense-making that would be helpful to me and to other mothers or parents? Would it be useful in helping practitioners to widen the scope of knowledge and practices in dealing with families, and those individuals who compose them?

The three social constructionist ideas that formed the initial focus for my work were:

- I was intrigued by the idea of multiple beings or selves; that we are polyphonic (Gergen, 2009).
- The idea that identity is a social or relational achievement, that we create an identity through our relationships, was meaningful but almost outside my grasp.
- I was curious about dominant discourses in our culture and how they offer us ways of talking about ourselves that are constitutive rather than representative of reality. I wanted to know how to render discourses visible.

As I became aware of other possibilities during my study, I opened up my inquiry to look at what other discourses were abounding and what other mothers’ experiences were, and how these possibly were similar, or different, to mine. McNamee’s (1996) definition of self includes the “confluence of relational membership in various and multiple discursive communities or an individual’s meanings and experiences.” This would imply that not only would I entertain a heuristic, or sense-making method of inquiry into my meanings and experiences, but an inquiry into the discourses of the various communities that are part of the world of motherhood or “mothering,” a site of competing and contentious discourses in the Western world (DiQuinzio, 1999). I reminded myself often that Aileen had been curious about how “Edward’s mother” had developed, and how this voice had dealt with the challenge of having a different child. Aileen encouraged me to write about it so that others could learn from me.

3.3. Aims

My dissertation is an inquiry, based on the premises of social construction, into how we become who we are through our relationships with others within the culture in which we live. In particular, I endeavoured to inquire into my own understanding of what happened while raising my son, and how I was affected. I wished to reframe the unpleasant aspects of my experience, and to incorporate these altered and alternative perspectives into my life-world by storying my life differently. Additionally, I invited others into a dialogue about their experience of being a mother of a child considered different, and how their experiences shaped them in becoming how/who they are today. And finally, I wish to write these stories in a way that might prove beneficial to those who work with mothers and fathers, families, friends and authorities, so that they may hear an alternative reading of mothers' experiences.

The focus of the three notions I initially had developed as my inquiry advanced and I found my aims to encompass the following practices:

- Restorying a life – finding alternative stories, and other methods or perspectives that help to change the meanings we make in our lives;
- Facing and reflecting on the construction of my 'reality' of what happened in my life and my children's life, and the effects, or experiences, thereof;
- Deconstructing the dominant cultural discourses that invite mothers to be solely responsible for not only producing healthy children, but 'psychologically' well-adapted children;
- Finding 'useful, liberating, fulfilling and rewarding interpretations' and welcoming the idea that there is "no true or valid interpretation" (Crotty, 2010: 47);
- Adopting a theoretical perspective, a philosophical stance that allows the inclusion of my voice and the meanings that I construct with other voices around me.
- Demonstrating Gergen's concept of 'relational being' (2009) and also
- Giving an example of how McNamee and Hosking's idea that "auto-ethnography could be developed in ways that more fully realize the potential of a relational constructionist perspective (McNamee and Hosking, 2012: 57)

3.4. A possible hypothesis

The relational constructionist requirements of self-reflexivity or reflexive critique (McNamee, 2000; McNamee, 2004) tell me to be aware of the effects of my truth, or my story, upon myself, the community of mothers and those with whom we deal. I should not allow this story to become sedimented, i.e.,

too “steadfast and secure” that freezes all meaning, and allows “little possibility for deviation and transformation” (Gergen, McNamee and Barrett, 2001). Not only should I question my logic, but I should be curious to understand how others’ logics are constructed. This leads to me to inquire not only about other mothers’ experiences and meanings, but those whose logics or moral orders confront and oppose the mothers. I find myself teetering on the fine line of maintaining my position while inquiring respectfully into the logic of those with whom I have so often found myself in opposition (McNamee, 2008).

My inquiry has, therefore, evolved to take into consideration the moral orders of others, while continuing to ask the question, “How can we alleviate the mothers’ guilt?” My hypothesis would be that if we were to reduce these disabling experiences of dominant discourses around mothers, perhaps by changing the way we help and assist them, we would all be better equipped to help the children who are positioned as being different.

I hope, together with the mothers, that we can find ways to alleviate “mother’s guilt.” My research therefore aims to describe in order to increase our understanding. By undertaking this inquiry I am well aware that I am “intervening” in and “transforming” practices, not only my own way of describing and understanding. Those whom I have encountered in this process have also undergone some change. My inquiry will therefore follow the steps of narrative inquiry (McNamee and Hosking, 2012) from an understanding of my story, i.e. in the sense that I give it a form of attention that I had not done hitherto, to an exploration of the coordinations (McNamee, 2008) that form the rituals or patterns of interaction between mothers and professionals, so that we may have one perspective of how we came to be in this situation.

From an understanding of how we got to this situation, I will discuss what I have learned through my academic reflexivity, i.e. my reading of the literature that has been part of my exploration, and the talks I have had with a number of professionals so that I can provide alternatives of how we can go on together (Wittgenstein, 1953) in order to create better social worlds (Pearce, 2007).

3.5. My journey of inquiry

As with the majority of inquiries we set out on a journey that takes us in different directions and using different means. To better explain my methods, it might be helpful to also describe my inquiry as three different and contingent journeys, or phases.

1. Inquiring into my life by examining written documents

The first phase was, from the spring of 2009, to February 2012, an inquiry and collection of data about my life as a mother of a son who was later diagnosed with Klinefelter syndrome, and the impact of that diagnosis on his life and consequently on my life. My method of inquiry focused on the reading and collating of information about myself and my son from all forms of written

documents: my personal journals; my letters to my parents, other family members and friends, and their responses; teachers' reports about my son's schooling; reports from the medical doctors and other professionals; reports from the Swiss disability assurance (Assurance Invalidité, AI) that they did not want me to read; and legal documents. It was my intention to un-cover the different stories being told by the various people, practitioners, so that I would be able to weave the various elements together and tell a "whole" story. This was possible because as my advisor, Sheila McNamee, has said, I am a "pack-rat", although I personally prefer the term, "squirrel" because I have hoarded almost every piece of paper pertaining to my life as a mother and in particular to Edward, my son, and I have now been able to open them up in the autumn of my life and feed off them. During this phase, I came to understand that I was suffering from, what others may call, trauma, and the act of writing this story helped me to incorporate, what I saw, as the different violent, albeit unintentionally-committed, acts against me and my son. My original intention for my dissertation was to re-story or re-author this story, something I am not sure I have been able to do. I have, however, changed the purpose to serving as an example for others, and with the hope of changing the relational dynamics in which mothers find themselves. The method I have used comes under the term of auto-ethnography.

During this phase, I wrote that my personal goal was therapeutic: to be able to think back of difficult situations and painful memories without the accompanying pain that has haunted me for many years.

2. Inquiring into the lives of other mothers with children in difficult situations

During the first phase of writing, I stepped outside of it to inquire into the experience of other mothers in the Swiss French area. My purpose of undertaking this second inquiry was to hear other mothers' experience with their families, friends, teachers, medical and similar professionals, and how these relationships and experiences either helped or hindered them. I chose to interview five mothers whose children had been diagnosed with Attention Deficit and Hyperactivity Disorder (ADHD). I had already found in personal conversations that they had had similar experiences with professionals to mine. My intention was to document their experiences and draw comparisons, similarities with theirs, within this geographical area at a particular time, in the past twenty years. Being of British origin in a Swiss-French environment, I was interested as to whether my experience was different from those who were born and raised in the Swiss-French area. I wanted to know if I had been the recipient of particularly different actions by those who are professionally involved in the education and health of children because I was considered a foreigner. I came to understand that if the way we are treated indicates equality, I can truly be considered Swiss. The method I have used comes under the term of narrative interviews.

3. Making use of my story and my experience – offering alternative stories – inviting others into alternative forms of relating for three different groups of readers

This third phase is to reflect on my experience and that of the other mothers, and to make some form of sense out of it, so that it serves some purpose for my readers. The question of contribution to a body of knowledge was not always in my mind, although I often reverted to it, when I found that what I was writing made little sense. During the first phase of writing, I could have decided to embark on an analysis of relationships between mothers and their different children, or mothers and fathers of different children. Yet what made the tears come to my eyes was talking about the lack of support that I experienced. Then, in the second phase of inquiring into the lives of other mothers, I heard stories of how they had been talked to by professionals and how they had experienced those conversations. This last phase, although I had been researching alternative stories, was influenced by attending Sheila McNamee's course on Communication in Healthcare at the University of New Hampshire in February 2012, which opened my eyes to the writings about the medical culture.

3.6. The experience and purposes of writing for different readers

In this section I differentiate between writing for myself, for other parents, and for professionals.

a. Writing for one's self

In the first phase it seemed, with hindsight, that I wrote for myself. Not only was I intent on unraveling the story so that the thread would be visible and lead from one place to the other, I also put pieces of the puzzle together. Pennebaker (1997) writes of the value of writing to promote physical well-being and mental health, and it was not until February 27, 2012, when I finished the last chapter of the story and sent it off to my advisor, that I realized "I had put it to bed". This work allowed me to, as we say in French, "mettre à plat", lay it all out in front of me, the majority of events in sequence, and to understand the "battering" that I took for so many years. From an academic perspective, my aim is to explore the workings and meanings of personal transformation through writing, so that I can invite others to do the same.

I would like to remind you that this is my narration of a story that demonstrates the way we construct social realities together. It has been no easy undertaking to read through the documents and reports, the letters and the personal journals, and to include it in my dissertation. I have sometimes felt guilt or shame that I was the author of particular texts: what sense of entitlement did I find myself so attached to that I would have written such a thing? Reading others' texts, I relived some of the effects of their "sense of entitlement" (Winslade and Monk,

2008: 95) that gave them to believe that they could talk in that way, or address me in that manner.

b. Writing for other parents

In our world of professional experts, parents are so often seen as ignorant, naïve even if they are well intentioned. The professional, expert advice has a tendency to invalidate the experience of parents, who are “experts through experience”. It is, perhaps, through an inductive method of collecting specific stories of experiences that we build up our knowledge base, one that is often reduced to “anecdotal” by the scientifically based, professional bodies of knowledge.

What became apparent during this inquiry was the lack of an overall framework that would help parents to make sense of their roles, responsibilities and obligations, i.e. including the elements of dominant cultural discourses, in order to develop useful practices with their children. In a world dominated by “mother blame”, so much professional discourse focuses on isolating the source of all problems within the mother-child dynamic and therefore alienating mothers for whom they are supposed to be providing support. From an academic perspective, my aim is to explore various, alternative and helpful discourses.

c. Writing for practitioners and academics

From the modernist stance of observing and describing parental and, in particular, mothering practices based on a deficiency or medical model, practitioners and academics may not realize the unhelpful effects of their statements. Perhaps I am being hopeful, perhaps naïve, in saying that we are in a transitional period towards post-modernity where the many different voices of all people involved in the world of children will be taken into account. For that to happen, accounts like mine are needed for professionals to understand the effects, or experiences, of their “expert” advice and research. In this sense I will be contributing to the body of knowledge that a doctoral dissertation is supposed to do. Gergen and Gergen write, that autoethnography can be seen as an “interpretive activity addressed to a community of interlocutors” (2000), which may stretch beyond the academic audience. It is my intention to cooperate with professionals so that their practices can be more helpful to those who they do wish to serve.

In this next part of my chapter on methodology, I describe the various methods that I have used during my dissertation. The following methods are described:

- Autoethnography
- Writing
- Voice dialogue – conversing with multiple voices in writing
- Narrative inquiry
- Re-membering

3.7. Cobbler's choice of methodology

Crotty (2010: 49) presents the notion of the *researcher-as-bricoleur* from Denzin & Lincoln (1994), who propose three different approaches to research. The first is that of the reflexive researcher asking herself, "Can I do this? Do I have the skills?" to be able to undertake this research. The second is taken from Lévi-Strauss' position, which is quite different, "What can I make of this?" as a wood-cutter would say looking at a piece of wood, as I look at the documents that constitute my raw data. The third is that of the innovator, who "recycles used fabric", to 'cobble together stories'. When I contemplate the stacks of documents, teachers' reports, medical reports, correspondence and personal journals, that constitute the majority of my raw data, I do not see any meaningful and possible form of research based on positivistic principles that will encompass the richness of this life. There are no discreet psychological constructs that would make meaning of the social world that I lived in and experienced with others. So I have cobbled together a story using these stacks of documents, using primarily autoethnography and narrative inquiry.

3.7.1. Autoethnography

Ellis (2004:31) writes, "As a form of ethnography, autoethnography overlaps art and science; it is part *auto* or self and part *ethno* or culture." Ellingson and Ellis (2008:450-459) see autoethnography as a social constructionist project that rejects the deep-rooted binary oppositions between the researcher and the research, objectivity and subjectivity, process and product, self and others, art and science, and the personal and the political. I have found that disclosing my own personal experience and inquiring about others' experiences has been a way of understanding how the personal is political. When the educational system criticizes mothers for the way their children behave, it is also because the system cannot deal easily in the current political situation with those children whose behaviour does not fit the requirements of the educational system. When people infer that we should be ashamed by our children's behaviour, they are inviting us to remain silent. It reminds me of what Tal, the cultural critic, says about bearing witness of what has happened to us. "If 'telling it like it was' threatens the *status quo*, powerful political, economic, and social forces will pressure survivors either to keep their silence or to revise their stories" (Tal, 1996:7).

Autoethnography, according to Maréchal (2010:43), "is a form or method of research that involves self-observation and reflexive investigation in the context of ethnographic field work and writing." However it is different from ethnographic fieldwork of observations and interviews, in that the focus is on the researcher. I become both the researcher and the subject of research, my own case study. As Ellis (2004: xvii) says, we start with our own life experience describing the situations, the feelings and reactions. However, it involves the cultural context within which we are situated. Ellis writes, "The primary purpose of personal narrative is to understand a self or some aspect of a life

lived in a cultural context” (Ellis, 2004: 45). Personal narrative fits the bill. My autoethnography is, primarily, the texts that I have collected and kept over the years. All of those texts were either addressed to me or given to me. Some of them I wrote myself, and I have preferred to present them as I wrote them in that situated time. Traditionally they would have informed my memoirs, and I would have written an autobiography. In the following section, I describe writing as a form of inquiry, as well as the use of the method of voice dialogue.

Denzin (2003) states that he values autoethnographic texts that do certain things, laying the ground for performative criteria. These things that he values are the following:

1. “Unsettle, criticize and challenge taken-for-granted, repressed meanings;
2. invite moral and ethical dialogue while reflexively clarifying their own moral positions;
3. engender resistance and offer utopian thoughts about how the things can be made different;
4. demonstrate that they care, that they are kind;
5. show instead of tell, using the rule that less is more;
6. exhibit interpretive sufficiency, representational adequacy, and authentic adequacy;
7. present political, functional, collective and committed viewpoints.”

I return to these criteria in Chapter Eight where I reflect on the value of this dissertation.

3.7.2. Writing

“I write in order to learn something I did not know before I wrote it.”
Laurel Richardson, 2005: 924

In this section, I write about my experience of writing my story and how it became a method of inquiry, a construction of identity, and a therapeutic practice.

Writing has played an important part in my life. I started my first personal journal on May 21, 1991, during the time when I was in couple therapy with the father of my children. I wrote on the first page that I hoped would “clear the confusion and bring clarity.” Had it not been for this writing, this dissertation might not have come into being.

In the first phase of writing this dissertation, I saw myself as “simply copying and pasting” chosen bits of letters and other documents related to my son, to depict the story of my life as a mother. However, it also allowed me to reconnect with the person I was at that point in time. An example is the bundle of letters that my mother had kept, that I had written to her and my father, starting in 1984 when I was expecting Edward. The person I was at that time is

the person I depict in my letters, the opinions I hold, the preferences I describe, and the relationships I maintain. Richardson (2005: 925) writes, “Language is a constitutive force, creating a particular view of reality and of the Self.”

However it was also “a method of discovery and analysis” (ibid: 923) to copy extracts from my diaries or from doctors’ reports, because, perhaps with the healing passage of time or some other form of emotional distancing, I was able to read – as if for the first time – the words written and comprehend the meanings involved. At least that is what it seemed like, as if there was some stable, universal meaning that I had not grasped. It became obvious, at moments, that the different knowledge or advice given by others who influenced my life was based on different assumptions. I could by now deconstruct those assumptions, those guidelines they held, and see how we saw things so differently.

One example is couple therapy in 1991 with Edward’s father. The psychiatrist assumed that I was a working mother, not the sole breadwinner. My request for more equal sharing of home and children responsibilities with my husband was not taken seriously. He assumed that I was working because I wanted to, which he inferred was a “selfish” reason, and one that did not exempt me from being fully responsible for the home and the children. He often told me that my request could not be taken seriously. Finally when he did listen to my description of our arrangement, and had his moment of “a-ha!”, he still found it hard to comprehend and to acknowledge the possible legitimacy of my request.

Writing can be considered a form of inquiry as an “additional – or alternative – research practice” in social science (Richardson, 2006: 923). Writing the above example forces me to examine what was going on, that was not written down in my diary, and to reflect on what was inferred. Through writing, as we put our thoughts and ideas down on paper or on screen, we can see them, organize them, restructure them in a different way, but we can also “grasp” them, clarify, analyze, interpret and understand them; we can make them comprehensible and meaningful for ourselves, and for others. We also rewrite them to include new knowledge. I rewrite as I reinterpret the above incident to include the new insights that come to me through my reflection. The story could continue to be rewritten. I am restorying my life, a reflexive and, therefore, therapeutic practice.

When I started to read and copy extracts from psychiatric reports about my son from the later years, I found myself weeping, bent over my desk. The reports served as reminders of what had happened, and how they contributed to what happened. I would try to continue reading and writing with my cheeks wet with tears. I would have conversations with the voice that was so sad. I thought that the crying would come to an end. I have a voice that has a positive attitude to crying, one that I learned in the cathartic expression of emotion taught in Co-Counselling (Evison and Horobin in Rowan, 1988). This voice invites me to

say out loud what is happening and how it affects me, and then repeat the sentence that makes me cry most. It believes that “crying does me good”, that the sadness and need to cry will pass and that I will feel better afterwards, which will allow me to think more clearly. However, my distress seemed immense to my husband and he encouraged me to seek out my former Jungian depth psychologist, Evy, for support. Evy had been my therapist from 1993 to 2004. She knew my story so I wouldn’t have to repeat myself, which was important to me. In July 2011, through our conversations and my reading, I came to a personal understanding and formulation, or a restorying, that I had had an experience which others call “trauma.” I wrote an e-mail to Evy on July 28, while I was reading Tal’s (1996) book *Worlds of Hurt; Reading the literatures of trauma* and quoted Wikipedia, to describe trauma, “A traumatic event involves a single experience, or an enduring or repeating event or events, that completely overwhelm the individual's ability to cope or integrate the ideas and emotions involved with that experience. The sense of being overwhelmed can be delayed by weeks, years or even decades, as the person struggles to cope with the immediate circumstances.”⁴ Following that e-mail, we talked about it in our session.

I wrote in my personal journal dated August 16, 2011 – *Session with Evy*

We talked about trauma. I told her that I had written the chapter “coping and hospitalization”, all the recorded events and memories of 2001. At one point, she looked at me and repeated a question, “Do you think you were traumatized by the diagnosis of Klinefelter syndrome or by the way you were treated by the doctors, the social assistants and John?” I wasn’t ‘traumatized’ by the knowledge that Edward had this genetic syndrome. I was ‘traumatized’ by the constant bearing of the responsibility and the lack of support from my environment.

Seeing that I am of an inquiring nature, I decided to inquire into different perspectives of trauma took me to Van der Kolk (1987: 31) who writes, “The essence of psychological trauma is the loss of faith that there is order and continuity in life. Trauma occurs when one loses the sense of having a safe place to retreat within or outside oneself to deal with frightening emotions or experiences. This results in a state of helplessness, a feeling that one’s actions have no bearing on the outcome of one’s life.” Helplessness and hopelessness have definitely maintained a grip on me for many years.

What became apparent was that the many years of dealing with school teachers and the social assistant, Mrs. S., had worn me out. The diagnosis initially held out new hopes for treatment, and that receiving such little information and support, Edward had broken down and been hospitalized, and from that moment on, I seemed to be alone.

⁴ Retrieved from www.Wikipedia.org/trauma on July 28, 2011

In their article, “Forming a story: The health benefits of narrative”, about the practices of writing about personally traumatic events, Pennebaker and Seagal (1999:1248)) state that when we translate experience into language, through writing, it “changes the way the person organizes and thinks about the trauma” because giving it form of a different kind, one that structures and gives meaning, it makes the experience “more manageable” in that it “facilitates a sense of resolution, which results in less rumination and eventually allows disturbing experiences to subside gradually from conscious thought” (1243). This has been my experience during the writing of this dissertation.

Writing about difficult experiences can become a habit, and a way of dialoguing with one’s self. Ellis (2004:33) writes, “I tend to write about experiences that knock me for a loop and challenge the construction of meaning I have put together for myself. I write when my world falls apart or the meaning I have constructed for myself is in danger of doing so.” That writing can be an exploration of different perspectives and allow for a different narration to be formulated seems clear. Why is it that I have felt so strongly about writing publicly about this? I find that even beyond writing publicly about this matter of motherhood, I am now speaking publicly about the topic.

3.7.3. My ‘integrating’ or ‘reflexive’ self

Prior to starting the Taos Tilburg PhD program, I had the good fortune to learn the practices of Voice Dialogue, created by Hal and Sidra Stone (1989), starting in 2006. The Stones state that, “Voice dialogue is a communications tool as well as a method that can be used for getting to know ourselves better. It is neither a psychotherapeutic system nor a substitute for appropriate psychotherapy when this is indicated.” Their method is based on theories drawn from Jungian depth psychology and cognitive behavioural therapy. It was through this approach that I learned to construct a reflexive voice in writing. I have found it helpful to distinguish between the different discourses and subject positions in my thinking by writing the dialogue down. This integrative part of me is not a core self, but a part of me, or a self or a voice that has been constituted through relationship (Gergen, 2009: 149) by learning a particular approach to self-reflexivity.

When I talk of an “integrative, reflexive self” that I learned during more than twenty days of training during the period of 2006 to 2009, I refer to what the Stones call the ‘aware ego process,’ a subpersonality which is addressed at the end of a Voice Dialogue session by the therapist in a reflection on the session. Rowan (1990:10) points out that it is not easily possible to “reify the subpersonalities” because they are actually “processes which are actually very fluid and in change.” It would seem that this is a coherent approach to change in a person, we change through the development of potentials. In a Voice Dialogue session the facilitator converses with ‘subpersonalities’ and allows the subpersonality to reflect on his/her positions. The Stones encourage people to use the method in a playful way, not to take it too seriously. Similar to Tomm’s

Internalized-Other interviewing (1994), the method allows the client-person to speak from the position of an internalized other, usually a person. Lysack (2002) has written an account of the process of internalized-other interviewing, in which he describes the difficulty of addressing a person by another name. His questions are similar to those that could be asked in a Voice Dialogue session.

In a typical Voice dialogue session, the facilitator will guide the client-person through a number of steps, starting with a discussion on how things are going generally, and specifically what the person would like to work on in the session, sitting in a chair opposite the facilitator. This position is the position they call the “aware ego process.” Following this, the facilitator will propose that a certain voice or subpersonality is explored. The person is invited to move to a place in the room where she can give expression to that voice, or it could be that the person moves their chair, in a way similar to the Gestalt two-chair exercise. The facilitator then proceeds to ask the subpersonality a number of questions to explore the thoughts, opinions and experiences of that subpersonality. The subpersonality is addressed as a person, and the facilitator and the subpersonality talk of the client as if she were a third person. For example, if you were to interview ‘my good little soldier’ (*‘mon bon petit soldat’* as he is known to me in French), we could talk about my role in Kate’s life, what I make Kate do, what hopes and intentions I have for Kate, but we could also talk about my origins, my gender, and my physical posture and gestures. Following the Stones’ recommendations, when the exploration comes to an end, the facilitator would invite the client-person to return to the ‘aware ego position’, center herself by asking a few questions such as, “what did you learn from that voice?” and then invite the client-person to take up an opposite subpersonality, such as ‘the part of you who rebels against the good little soldier or the part of you that does not do what everyone expects of her’. After this second exploration, again, the client-person returns to the ‘aware ego process’ and talks about the opinions and thoughts of the subpersonality. The facilitator often summarizes the two different positions, recorded in her notes. The client-person is not requested to renounce a subpersonality, but to take what is useful and helpful from each one. There is a similarity between Narrative Therapy and Voice Dialogue in that both methods externalise a part or a problem, and allow it to be discussed, and to be viewed differently. However, Voice Dialogue does consider that all these voices are part of the person, to be integrated, which is more similar to psychodynamic methods.

I would like to show you how I developed my method, incorporating Voice Dialogue, to write a dialogic conversation between my voices.

From the various authors (Manné, 2006; Stone, H.& S., 1989, and Stone, S., 1997) and the training I undertook, I fashioned a method of writing the dialogue between two voices starting in January 2009. Armed with a list of questions taken from our practice and various documents, I wrote in my personal journal, the answers to the questions.

I wrote in my personal journal on March 2, 2009:

I have taken and adapted the questions from Sidra Stone's method for talking with these voices.

1. *Exploration of each self*
 - a. *Who are you? What is your name?*
 - b. *What gender are you?*
 - c. *Tell me when did you first appear?*
 - d. *What's important to you?*
 - e. *What do you think of Kate?*
 - f. *How is she coping?*
 - g. *What does she do well?*
 - h. *What do you disapprove of?*
 - i. *What about her work?*
 - j. *What about her relationship with Jean-Luc?*
 - k. *What about her relationship with her children?*
 - l. *What about her studies?*
 - m. *How does she take care of herself?*
 - n. *Who are you loyal to?*
2. *Challenging / pushing back boundaries*
 - a. *What options does she have?*
 - b. *What is non-negotiable?*
 - c. *What else could she do?*
 - d. *What would please you, what would you approve of?*
 - e. *What damage do you do to Kate?*
 - f. *When she pleases or appeases you, what is she giving up?*
 - g. *How do you sabotage her, when she has to do things that you don't approve of?*
3. *Reaffirming learning and change /transformation capabilities*

Talk to the protector/controller:
You who takes care of Kate, who protects her and controls her, what will you allow her to try out in these coming days or hours?
4. *Integration time*
5. *Review: Notice how far you have come. What is going well for you? What is new and different?*

As an example, I wrote in my personal journal on March 4, 2009:

The perfectionist: I guess I'm a remnant of Kate's past. I appeared in Kate's life when she was ten years old. I sound like Kate's father. I think Kate is a hard worker. She really does what is expected of her. And if she doesn't, she feels guilty. I like it too when she has finished some piece of work. I have learned to appreciate her abilities.

On March 30, 2009, I wrote:

Over the past few weeks I have recorded, written down the voices in the morning as they wake me up. I have listened to such a range of voices. I have brought up a whole lot of unspoken fears into awareness. I have become aware of the voices that inhabit me. I've met:

- *The committed pusher. The part that does everybody else's part as well as my own*
- *The perfectionist who needs to keep on learning*
- *The bad catholic child who deserves her bad life*
- *The inner matriarch who is fed up with my husband*
- *The old body who is tired and ill*
- *The pusher who pays to be in a relationship*
- *The victim of the pusher*
- *The creative, reflective voice*
- *The rebellious daughter, fighting for survival*
- *The part who is never believed*
- *The clown who relieves the tension*
- *The intelligence who knows*
- *The part who was driven crazy by a certain person*
- *The protector-controller who doesn't want me to change*
- *The pleaser who hates to be rejected*
- *The visionary who can't get things done*
- *The slave*
- *The part of Kate who is waiting for her to hear her call*
- *The potential*
- *Her father's fear*
- *Little frightened Katie*
- *The angry sibling*
- *Patsy, the powerless problem stater*
- *The powerless, hopeless part*
- *The ambitious, competitive part*
- *The moaner*

On March 31, 2009, I started writing in two columns. In the left column, entitled the Inquirer, I wrote the questions, and in the left column, entitled the Responder, I wrote the answers. I kept my list of questions and added more. As time went on, I found it easier to come up with questions, which I continued to include under the column of the Inquirer. I could almost hear them formulate while I was responding. Below is an example.

The Inquirer	The Responder
Who are you?	I feel more like an emerging voice. I'm sure I've been here, but it's Kate's writing

	and reflexive observation that is bringing me up.
Who are you loyal to?	Order and clarity
Oh I recognize you. What purpose do you serve?	I assist Kate in making sense of her life, her work, her thoughts. I help to dig up the confusion, bring it into the light, and examine it. It reminds me of Marion Milner's (1934/1952) book <i>A life of one's own</i> .
So what do you make of this way of working?	It is more useful than psychoanalysis because it is a meta-position. I stand to the side and observe. I can separate out the voices and recognize their individual energy, their purpose and beliefs, and their role in Kate's life.
What do you want for Kate?	I want her to understand, to come to terms, i.e. accept that she has a multitude of voices inside her that make up who she is, and that there are also strengths that help her in life.
It is nice to hear something positive after all the shit she's been through.	Of course by bringing the voices to light and listening to what they say, Kate starts to act as Kate, master of the voices.

This method accompanied me throughout my dissertation, especially during the difficult moments when I felt overwhelmed by the reports I was reading. In Chapter Five, under Point 5.4.6.2., I will show you an example of how I used it to reflect on the day Edward was diagnosed. As I have already said in Chapter One, I find myself doing what others would call ruminating. I become aware of repetitive thoughts, telling me over and over again. By writing these thoughts down, I seem to be able to stop the repetition. It also helps me to be able to address the issues raised, which in turn seems to relieve the grip that these thoughts have on me.

In this section, I have described the techniques of writing and self-reflexivity that I have drawn on within the method of autoethnography. In the next section, I describe narrative inquiry, a way of drawing others' voices into the discussion.

3.7.4. Narrative inquiry

“[N]arrative inquiry is a profoundly relational form of inquiry”
(Clandinin, 2007: xv)

Narrative inquiry focuses on the lived experienced as narrated by the people who have lived them It is defined as a “distinct form of discourse: as meaning making though the shaping and ordering of experience, a way of understanding one's own or others' actions, of organizing events and objects into a meaningful

whole, of connecting and seeing the consequences of actions and events over time.” It is also “still a field in the making” (Chase, 2011: 421).

A part of my data is from the interviews I conducted with mothers of children who were diagnosed with Attention Deficit and Hyperactivity Disorder (ADHD), sometimes called by its variation, Attention Deficit Disorder (ADD). My intention was to inquire as to how other mothers related what had happened, and how it happened with their children in the Swiss-French area. Hélène Ducret-Baer, the president of the ASPEDAH association, agreed to be interviewed and to inform other mothers. They asked to be part of the research. The interviews were between an hour and a half and two and a half hours. The full transcripts from the interviews were sent to the five mothers. It gradually became a possibility that I could edit the stories and give them back to the mothers and the association as a gift in return for being interviewed. Again, all of them agreed to have their stories published. Four of them chose to be presented with different first names for themselves and their children. The edited texts were sent to them for approval. The five stories were published in a book in time for the symposium on ADHD, mentioned in Chapter 3, in February 2011.

I sent the women a text about myself, my inquiry, and the three questions to trigger their stories. The questions were (Lindley S., 2011: preface):

1. Tell me about situations or a situation in which someone made a remark that helped you in your responsibility as a mother. How did it help you?
2. Tell me about situations or a situation in which someone made a remark which you found hard to accept. How did you react?
3. What are the resources or characteristics that you have developed since you became a mother? How did you develop them? In which relationships have you been able to reinforce these resources?

The choice of questions was based on my knowledge of “behavioural-based interviewing” used in organizations for selection and development purposes. The intention was to gather specific examples or stories rather than generalized ideas. The first question was influenced by my knowledge of Appreciative Inquiry (Cooperrider, 1987) and intended to highlight how professionals or others could be helpful to mothers. I positioned it as the first question so that we could talk about ‘positives’ before talking about ‘negatives’. I have found in interviewing for selection purposes in organizations that inviting candidates to talk about positive experiences improves the relationship and allows the candidates to show their “best selves.” Some of the mothers, however, decided to tell me the negative stories first so that they could finish with the positive stories. Some were surprised that I did not want a biographical or chronological account. They were used to telling the stories about their children “from the beginning.”

The second question was influenced by White's (White and Epston, 1990, White, 2007) idea of "unique outcomes" which would also reflect "acts of resistance," that is those moments when "whenever [they] were badly treated, they resist" (Wade, 1997:23). My intention was not to depict them as helpless agents, but to invite them to describe thicker and richer descriptions of themselves in having more control within the context that they lived.

The third question was influenced by social constructionist thinking of how we "narrate" ourselves "in terms of relational process" (Gergen in Wetherell et al., 2001: 247). I intentionally chose words, such as "characteristics." I did not want to depart from the more commonly used terms and ideas, such as the cognitivist idea that we construct ourselves within ourselves. I am aware that I was following a modernist narrative convention. As Gergen (ibid: 255) writes, "One is not free to have simply any form of personal history. Narrative conventions do not, then, command identity, but they do invite certain actions and discourage others." However, the outcome is the one I wanted, in that the women described themselves as having developed positively. In other words, they seem to be saying that they like who they have become.

Fraser (2008:88) writes about the use of narrative methods where people "tell their stories and exchange ideas, hoping in the process that they might develop new ways of understanding their work and themselves." This is what I think I experienced. It allowed my work to move from the phenomenological, focusing on my own experience as a personal experience in an individualistic manner, to extending my knowledge of what seemed to be a collective experience amongst women of children in difficult situations in the Swiss-French area.

Fraser writes, "narrative methods are unashamedly non-scientific. This means that those who use narrative methods do not claim to be neutral or objective. They are not 'social scientists' who 'discover facts' so as to assert 'the real truth of the matter', or 'experts' who 'know what's best,' but people who are curious about the world and the people living in it. Mostly they are curious about how people make sense of their worlds, and how these meanings affect themselves and others" (ibid: 88).

In my work my intention is not to provide a "discursive psychological" analysis of each of the women that I interviewed. There are individual differences of how they perceived negative or positive remarks and how they reacted to these remarks. I hoped that by providing a collection of stories that included the effects of dominant cultural discourse that we would increase our understanding of the "human experience" of these mothers, myself included (Pinnegar & Daybes in Clandinin, 2007:3- 34). As Gergen and Gergen write about "Frieda Haug and her students [...] arranged situations in which women shared their stories of their emotional development. Through their mutual dialogues and interpretive sessions they were able to reconstruct their past, and to generate a sense of how the culture creates femininity" (Gergen and Gergen, 2003). I

would hope that my work has generated a sense of how the culture creates motherhood.

Narrative inquiry has allowed me to inquire about others' experiences and juxtapose our experiences. The conversations that were part of this form of inquiry gave me a sense of belonging to a particular group of mothers, where I am considered "one of them" and provided me a very different experience from that of positioning myself as a neutral, external observer. Being part of the group of mothers, we are part of a community and by writing together, we have been able to control the representation of our experience, without being silenced or rewritten by others (Tal, 1996:7). Gergen writes, "From a relational standpoint, one of the shortcomings of most narrative research is that the subjects don't *fully* speak for themselves. Rather, the researcher is placed between the reader and the narrating individual. In this sense, the narrative is "managed" by the researcher, at times for academically instrumental purposes (e.g. "to demonstrate my point"). In any case, the reader is often left wondering, "Whose story is this, anyway?" (2009: 237). I have therefore differentiated between my voice and the mothers' voices in the accounts in Chapter Five.

I have also brought together the stories that pertain more specifically to Attention Deficit and Hyperactivity Disorder (ADHD). My reasoning for telling these stories about ADHD specifically is to highlight the debates about a disorder. A disorder, like a genetic syndrome, is a social construction. The American Psychiatric Association is currently revising the description of ADHD for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorder. It is interesting to note how the topic elicits such differences of opinion. It is not easy for mothers to find themselves situated within this discourse. I have grouped the stories according to six points, which are:

1. How was the diagnosis made?
2. What did the diagnosis mean to the mother or to the parents?
3. What was the choice of treatment?
4. If Ritalin or another similar medication was taken, how did the child react?
5. Who knows that the child was put on medication?
6. Did other doctors question the diagnosis and the medication?

The interviews were held in French. After transcription, they were edited to render them less like spoken language and more like written language. I conducted the transcription with the help of my husband and my daughter. The women involved received both the transcription and the edited text, which they agreed to have published. I published the book (Lindley S., 2011), which is entitled "*Qu'EstCeQueJeNeDoisPasEntendre?*" which more or less means "The things I have to listen to". The original title is a play on the correct spelling, "Qu'est-ce que je ne dois pas entendre?" and reflects the forcefulness of having to listen to other people's opinions.

I have translated the excerpts in this chapter from French into English. As I do not speak colloquial English often, and do not grasp the nuances and idiosyncrasies between localized versions of the English language, I have kept the language as close as possible to the French language. It may seem stilted or formal to you.

I also pick up on various comments or statements made by the mothers in the interviews I shared with them and elaborate on them. This may be a form of critical analysis in the sense that I will pick up on what I perceive as ideologies that inform discourses, however, you will find, that I may chose those that resonate with me. My intention is not to position myself as the ‘expert’ and translate the mothers’ talk into some form of theory. The conclusions that I draw are my own and do not necessarily represent their views.

You will find these stories in Chapter 5. I have also included how they described the experience of being interviewed and invited to tell their stories.

3.7.5. Re-memembering

I used the approach of re-memembering, which I described in Chapter Three, after having translated and written up the mainly negative descriptions of Edward’s school years (in Appendix A). Before feeling totally overcome by the feelings of anguish that these descriptions elicited, I wrote to my family and friends asking for their stories of Edward. The request I made was to a great extent based on the approach of the “Reflected Best Self exercise (2004) of R.E. Quinn, J.E. Dutton and G.M. Spreitzer of the Michigan Ross School of Business, which I use in my organizational development consulting work in organizations.

I wrote, “As you may know I am doing my phd dissertation around Edward's life and his diagnosis - I am in New Hampshire for the month of February finishing it. There are times when I find it difficult to read all the documents (medical and teachers reports, etc.) about him that are so negative, because that is not everyone's experience of Edward. I would really appreciate it if you could write a short story of a time when Edward was at his best, when he did something with you, or you heard about him doing something, and you thought it was good. I will include your stories in my dissertation as examples of how we can think of Edward differently. You too may have a story about Edward, a different story. Perhaps you will want to dip into Appendix B and hear about Edward as he is seen in February 2012. Maybe it will reassure us that I did do a good job of being a mother to know that amongst his multiple selves, he is seen by others as the selves that they described. The process I engaged with here might usefully be described as a form of deconstruction.

3.8. Questions of ethics

In the “Ethical guidelines for dissertation research” established by The Taos Institute, we are asked to consider the ethical implications of our work, by

considering the two inter-related issues of 1) How does the research construct the world?; and 2) How does the research affect relational process?

My research favours the stories recounted by a group of mothers whose children have been diagnosed, or categorised, as different, above others. I choose to represent those mothers as being part of a discourse, as a group of people whose voices have not been heard in the Swiss-French region. Only one of the mothers wanted her name to be known, the others chose to stay anonymous.

I write for Edward, my son, who could be considered ‘a more marginal survivor’ (Tal, 1996), and whose voice has not been heard. Initially I had hoped that we would write together, to restory together, but it turned out that Edward did not want to, and that the work became my re-story. Edward, my daughter Beatrix, their father, John, and my husband Jean-Luc, know about my undertaking and have given me permission. Edward’s response to my request for permission in June 2009 was, “Oh cool, just wait until my friends know my mother is writing a book about me.” We have, however, chosen not to use his nickname nor his surname.

There are a number of things that I have chosen to omit in my work. I have tried to focus on what is important in relation to Edward and the notion of the social construction of identity of a mother. Badinter (1980/81) says that we cannot write about mothers without referring to their environment. She writes, “The mother, in the customary sense of the word (that is, a married woman with legitimate children) is a person who is relative and three-dimensional: relative because she is thought of only in relation to the father and to the child; three-dimensional because, in addition to this two-fold relationship, the mother is also a woman – that is to say, a unique being with her own aspirations, which often have nothing in common with her husband’s hopes or her child’s desires. Any research on maternal behavior must take into account these variables. (Badinter, 1980/81:3)

Within my personal account, Appendix A, I have also chosen to omit certain texts that relate to past and present conflictual situations within my family. As language is constructive, I do not wish to construct these conflicts as enduring. This is a difficult choice because readers may feel that I am hiding something, that the picture is not complete.

3.9. Conclusion

In this chapter I have outline the qualitative research methodologies that I used to undertake my inquiry. Bava (2005) writes that research is not simply a report. Research can be seen as a larger performance with multiple parts involved. The writing of this report is one of these parts. Autoethnography endeavours to replace the notion of validity with the act of reflexivity (Gergen and Gergen, 2000) and thereby relinquish the “the god’s eye view” and reveal my work “as

historically, culturally and personally situated.” In the next chapter, I offer you various accounts of mothers’ experiences, a “multiple voicing” which provides “a potentially rich array of interpretations or perspectives” (Gergen and Gergen, 2000).

Chapter 4: Constructing a mother identity within the available discourses

“Once, even the kindly Dr. Spock held mothers solely responsible for children.”

Gloria Steinem, *Outrageous acts and everyday rebellions*, 1995:162

In this section I introduce the themes related to motherhood through a personal account of my two grandmothers. I then describe how early psychoanalysts wrote about women and mothers, and in the same vein, how medical discourse informs mothers and others about mothers. Situating my inquiry into discourses on motherhood with children in difficulty, I have included my own and five mothers' stories about how their children became diagnosed with Attention Deficit and Hyperactivity Disorder.

My aim of this chapter is to show how medical, technical or scientific discourse, which becomes part of our everyday language, can influence the way we think, talk and write about people and, in particular, mothers of children who have difficulties. I draw on historical, traditional health communication literature to discuss medical dominance, and the roles of doctor and patient. The permeation of this medically or scientifically based discourse in our everyday worlds can hold mothers responsible for their children. I relate three situations, which happened in the last three years, that demonstrate the modern power of medical discourse. I also draw on relatively unknown literature about mothers' lack of well-being that have been researched with mothers who have children who have intellectual disabilities. This discourse is drowned up by the discourse that holds mothers responsible for their children's well-being, development and successful adaptation to Western success factors. In the last part, I discuss the possibility of guilt and shame as reactions to the lack of support and the constant reminders of responsibility. When mothers are held responsible for their children and do not live up to the expectations of others, we may invite them into cultural performances of guilt, shame and anger. I also discuss the notion of “mistaken shame” and the attribution of shame on mothers as a form of modern power.

4.1. Themes of motherhood

In this section I present various points about motherhood, starting with two stories that I have constructed over the years about my grandmothers. These examples demonstrate what some women experience when they become mothers, and the themes that are embedded. I also draw on my own experience within the historical place that I occupied. I also discuss what categories of mother could be drawn on, which demonstrates that mothers actually come in various guises. And finally, I discuss motherhood as a practice, or a discourse.

I come from a matriarchal line of Irish women. My grandmother, Katharine Nuttgens née Clarke, reportedly studied mathematics under Eamon de Valera at the turn of the 20th century in Dublin. I say reportedly because my parents' inquiry into the life of my grandmother, after whom I am named, has not found the school or university that she was said to have attended. Katharine died when my mother was six years old in 1937. Like so many women, my mother - who has tried to learn more about her foremothers - has typically found that there was so little written about women. My grandfather, Joseph E. Nuttgens, wrote an unpublished autobiography from which I have learned more about my grandmother albeit from his perspective. According to my grandfather she was a fiery redhead, known to be subject to mood swings. The story goes that she became a teacher and was involved in some form of freedom-fighting activity perhaps under De Valera who later became the President of Ireland. She would have probably been active during the period before and after the Easter Uprising in Dublin. Her parents' home was searched on at least two occasions because of her activist involvement. For her father, an English sympathiser, it was intolerable. She left Ireland in 1923 for England, where she found a position as a governess or a tutor. In my grandfather's autobiography he wrote that he asked her if she missed her former life, and she said that she didn't. Once married, she devoted herself to bearing and raising her children while her husband worked and provided for the family. I am somewhat proud of my grandmother's legacy. From my understanding, she was a woman who fought for a political cause and used her education to earn her own living.

On my father's side my grandmother came from a modest, well-educated family and married a wealthy man in a liberal profession. She may have worked as a governess before she married. My grandmother and her mother were very active sportswomen. My grandmother played in tennis and golf tournaments, was known to have dived off the roof of the clubhouse into a swimming pool, and drove a motorcycle and car. There are photos in the family albums that show my grandparents skiing in the Bernese mountains of Switzerland in the 1920s. She was one of the first women to wear trousers, instead of long skirts, while skiing. She told me she learned the German saying, "Brust heraus und Bauch herein" (chest outwards and stomach inwards) from her skiing days, or perhaps from her German ancestors. When I was a teenager, I asked my grandmother why she had not looked after her children herself instead of having nannies and sending them to boarding school. This memory is kept alive through my parents' re-telling of the story. Grandma was supposedly quick to retort that "one had a social life to live, that one could not devote all of one's time to looking after children." I remember challenging her in a way that my daughter challenged me, her full-time working mother when she told me that she was going to be a "proper stay-at-home mother."

From these two depictions, I can extract many of the topical choices that women have had to face, and continue to face about education, work or employment, marriage, status, political involvement, and motherhood. I also know that it is

rare to scrutinize my grandfathers' lives and choices in the same way. Their work choices took priority it seems over their fatherhood.

I do struggle to understand how either one of my grandmothers could have been considered the weaker of the two sexes, a notion that has been with us for more than two hundred centuries. I can understand that to label women as the weaker sex is a discourse that positions women as inferior to men. To position us in such a way, reminds us that we should be conforming to the societal expectations of getting married and having children, and ignoring the trade-offs we find ourselves making in order to conform to these societal expectations.

I am part of the baby-boomer generation of women that had so many possibilities open up for them. Born in 1957, I entered into my teenage years in the seventies when the so-called sexual revolution was taking place. My parents, albeit both holding traditional roles, encouraged my sister and I to go on to higher education. My sister gave me the book *Our Bodies, Our Selves* when I was eighteen after she moved to Cambridge, Massachusetts. This book showed me the alternative to male dominated descriptions of women. The women write from their perspective and their experience, and perhaps was my introduction into the feminist stance. I achieved work-related status by the time I was twenty-four before I got married. I read de Beauvoir's *The Second Sex* (1949/1953) during my honeymoon. I was sure that my future husband, John, was intent on equality when he told me that it was alright for him if I worked when I became a mother. His step-mother, also the mother of her own two children, told me I would have to do it all (raising the children and running the home) by myself, but I was sure that he was going to help out. My father told me when I returned to full-time employment after the birth of my second child, Beatrix, that he expected me to give up paid employment after having children. So did most of the professionals that I encountered during pregnancy and after giving birth. The trade-offs I made, or the way I negotiated my identity as a mother within the available cultural discourses is described in more detail in Chapter Six.

4.1.1. Categories of mothers

Lakoff (1987) informs us about categorization in regards to mothers. He writes, "Categorization is not a matter to be taken lightly. There is nothing more basic than categorization to our thought, perception, action, and speech. He describes the 'central case' of mother, "where all the models converge" to include "a mother who is and always has been female, and who gave birth to the child, supplied her half of the child's genes, nurtured the child, is married to the father, is one generation older than the child, and is the child's legal guardian" (1987, 83). There are other types of mothers in his list, that he calls sub-categories and are deviations from the central case, some of which are "products of the twentieth century and simply did not exist before." There are stepmothers, adoptive mothers, birth mothers, natural mothers, foster mothers,

biological mothers, surrogate mothers, unwed mothers. It would follow, perhaps, that each type of mother would have a different experience of motherhood.

The mothers in my narrative inquiry, whose stories are told in Chapter Five, may well fit in to the central case. Some are divorced and remarried, myself included, and one has adopted her sons. We are all middle-class, heterosexual, of European descent, have finished school with some form of recognized qualification. Of the six of us, only two of us have continued to work full-time. Three have had part-time jobs; two of them have increased their working hours since their children have passed the age of sixteen. One of them is a stay-at-home, full-time mother. Two of us were divorced mothers for some time. We may well be considered “normal” or we blend into the population, at least we did until we became noticeable as mothers with difficult children, no longer “normal”. We all find the notion of “normality” difficult to deal with.

One of the things that I have found most intriguing during this inquiry is that some of the people I have talked to who seem so adamant about mothers being responsible for their children’s success (Lindley S., 2011: back cover) is that when I ask for specific practices, or the “shoulds” (in the sense of obligations), of motherhood, they seem to dry up. Shotter, in McNamee and Shotter (2004), highlights the “importance of all members of a speech community being trained into an extensive network of “normative expectations.” He continues, “It is these anticipations that work to hold all the different actions within that community together as an intelligible whole. Members failing to satisfy such background expectation in their actions will puzzle, bewilder, or disorient other members who will then question their conduct.” McNamee points out in the same article, that we have a tendency to talk from “abstract positions,” in “the form of statements like, ‘This is what I believe,’ ‘This is true,’ ‘This is right,’ and ‘This is wrong.’” (2004) Within such a “stance of certainty, abstractions invite hierarchy and thus, separation.” I would argue that by not recognizing the different actions of mothers, the community is infused with a sense of entitlement which does not require them to question the principles, values and beliefs that craft out of our day-to-day engagement with others (McNamee and Shotter, 2004).

4.1.2. Motherhood as practices and discourses

Motherhood is not an easily defined set of practices. It includes such a variety of topics that range from conceptual notions, such as “unconditional love,” to particular practices of “getting up in the middle of the night to soothe a child.” There is only one maternal practice that cannot be replaced by a man, and that is lactation (Blaffer Hrdy, 1991: 91).

The discursive practices – or the discourses – as explained by Foucault consist of “the social practices, investigations, talk and writing”, that is “all the sorts of

talk – by doctors, clergy, novelists, psychologists, moralists, social workers, politicians” that we link together to bring something into being (Culler, 1997/2011:5).

Culler (1997/2011:6) discusses Foucault’s work on sexuality and how sexuality came into being, and what was encompassed in this definition of sexuality. I invite you to read the paragraph below, and substitute the highlighted words ‘sex’ and ‘sexuality’ (with the exception of the word ‘sexual’) with the word ‘motherhood’. He says that the “fictitious unity” of sexuality comes to include:

“[A] range of things that are potentially quite different: certain acts, which we call sexual, biological distinctions, parts of bodies, psychological reactions, and, above all, social meanings. People’s ways of talking about and dealing with these conducts, sensations, and biological functions created something different, an artificial unity, called ‘**sex**’, which came to be treated as fundamental to the identity of the individual. Then, by a crucial reversal, this thing called ‘**sex**’ was seen as the cause of the variety of phenomena that had been grouped together to create the idea. This process gave **sexuality** a new importance and a new role, making sexuality the secret of the individual’s nature.”

If you had replaced those four words with the word ‘motherhood’, did you come to an understanding of how it is that we place a range of things, which are quite different from one another, and put them under the one term? Can we agree that the one abstract concept is filled with significations of the sort of values and beliefs from personal to political, and these come to constitute the norms of motherhood and thereby inform the expectations that we are hold of mothers?

Malacrida (2003: 19) quotes Nikolas Rose (1990:121) who “described how childhood, as ‘the most intensively governed sector of personal existence’ has in modernity become the focus of economic, moral, and developmental regulation.” I would argue that it is not so much childhood that is governed, but motherhood. Motherhood seems to be made invisible when we talk of childhood.

However, I also want to share with you how motherhood is a site of conflicting discourses that exist both internally and externally. The internal site seems to be a reflection of the multitude of discourses that exist in our social world. Being positioned as a subject within in multitude of discourses means that I have multiple and conflicting discourses as a mother. I am not always consistently coherent. I could belong to the fifty-five percent of the mothers surveyed in *The Motherhood Report* (Genevie & Margolies, 1987: 409), and perhaps of all mothers, who were categorised as “ambivalent,” that is for them, “motherhood was neither all good nor all bad.” But I do not want you to think of it as “ambivalence” as if it were an essentialist internal mental state, or

characteristic. That definition can imply, “this woman doesn’t know what she wants. One day it’s this, one day it’s that.” When that meaning is assigned, little attention is paid to how it came to be that one day a mother wants one thing for her child, and on another she wants something else. It could well be that mothers want both, and a professional might wish that she would prioritize or make up her mind because he or she has decided “she can’t have it all” or “she can’t have it both ways.” So as McNamee (2008) points out, we will investigate together what was said or written, and in what relational context it was said or written, and what were the perspectives (Charon, 1992:8) or rights and duties (Harré et al, 2009: 9). I will draw on the multitude of theoretical voices in these different domains to hopefully show the commonalities amongst them.

Burr reminds us that different and competing discourses of motherhood and “good and bad motherhood” exist, some of which are politically-driven. She invites us to look for alternative ways of re-presenting the “task of motherhood,” such as ‘helping one’s children to become self-reliant’ which may preserve our role of nurturing and guiding our children, but allow women who go out to work to claim the position of “good rather than bad mother” (2003: 123). This is what I hope you will find in Chapter Five, from the stories of the mothers, and in Chapter Six in my account.

4.2. The historical background of theories or stories about women and mothers

In this section I describe some of the dominant theories that have influenced our way of thinking about women and mothers in the Western world.

The historical background of the traditional roles of husband and wife, and the effects or experience thereof, have been described by many feminist writers, such as de Beauvoir (1949/1953), Friedan (1963), Greer (1970, 1984), Millett (1969/2000), and Rich (1976). Rich (1976) describes how in the United States of America women were considered the property of their husbands, long after the laws concerning women’s rights had changed in the United Kingdom. Badinter (1981) describes how, throughout many centuries, men’s well-being was considered their wives’ first responsibility. She describes how Catholic and French law were written in ways that placed women in subordinate positions to their husbands or fathers. Badinter (1981) writes how Rousseau’s writings placed woman’s domestic role and unpaid work as the primary caregivers of children as being of great importance in ensuring the economic prosperity of the nation. Rousseau instilled the notion that mothers were responsible for their children’s survival and physical health. Badinter (1981) then claims that Freud installed the notion that mothers were responsible for their children’s mental well-being. Psychodynamic theory was created by Freud to describe the processes of the mind as flows of psychological energy. The psychological forces underlie human behavior are based on the dynamic relations between conscious and unconscious motivations, and are the result of early childhood

experiences. Freud became the reference for the majority of developments in psychological, psychodynamic and psychotherapeutic work. No academic work would be considered complete without reference to his work.

Freud himself claimed to know little about women (1933: 362) and urged that others should continue their scientific inquiry into the psychology of women. However his “penis envy” theory has established itself within a discourse that continues to be considered valid for many professionals, and which positions women not only in subjugation towards men but in opposition to men. Women are supposedly envious of men’s superior status and angry for being relegated to their secondary status. Karen Horney may have described men’s “womb envy,” however that can be seen as a continuation of the discourse of opposition rather than in collaboration.

Following on in the psychodynamic vein, the British psychoanalyst Winnicott wrote mainly about the dyadic relationship between mother and child. His concept of the “good enough mother” described the “ordinary devoted mother” who lays down the foundations of her child’s health “in her ordinary loving care of her own baby” (Winnicott, 1964:17). His portrayal of mothers demonstrates how we came to be seen in our role of mothers, however, when he writes that the mother’s primary maternal preoccupation is an “extraordinary condition which is almost like an illness” (Winnicott, 1965b: 15-16) where she finds “the part of her that identifies with the infant, [she] is herself in a dependent state and vulnerable” (Winnicott, 1965a). Such language positions us within the medical discourse of illness and weakness.

Bettelheim (1967), another psychoanalyst, perhaps better known for his theory that unemotional mothers (“refrigerator mothers”) were the cause of autism in children, came to believe that children were relatively resilient and that “good-enough parents” (1987) were likely to do little damage. His view is similar to the Piagetian constructivist view that children develop in natural or normal ways as the inherent personality and intelligence of the child continues a defined path, relatively independent of the surrounding environment. Psychoanalytic discourse can position the child in opposition to his mother or father. Bettelheim writes, “Psychoanalysis tends to see the development of the self as coming about from the continuing relationship to the mothering person, and this is undoubtedly true. Much more questionable, however, is the facile notion that a child becomes socialized primarily to please his mother. Normal human development requires an integration of two experiences: first, of pleasing oneself, *and* also of pleasing others” (ibid: 242). This discourse of opposition rather than collaborative coordination is described in the daily practices of caring for children, in which the mother must be extremely attentive. As an example, in Bettelheim’s chapter entitled, “Proving oneself through contest”, he writes about how the child engages in a contest over food with his mother. Bettelheim prescribes that the mother who allows herself to be defeated in this contest will add to her child’s self-esteem (ibid: 239). Similar

advice is given for toilet training. He warns that should mothers not give in to the children, the children will develop neurotic traits (ibid: 242).

4.3. Medically informed advice on how to be a parent

In this section I describe how medical practitioners have become a centre of advice for parenting and mothering. This advice is so often based on their empirical observations of mothers and children outside the home and their theoretical positions.

From medical advice between medical practitioners to medical advice for parents there is one small step, one that may have economic benefits in addition to the professional respect and acknowledgements an expert may already receive. Bettelheim reflects the competitiveness of modernist discourse by claiming that his advice is the most beneficial while denigrating other forms of advice.

He writes, “Subconsciously we are leery of child-rearing advice even as we seek it” (1987:19). His second chapter entitled, “Expert advice or inner experience,” heralds the discussion of how it is that we as parents and how we can improve. Our reliance on ‘how-to’ manuals, books and articles permeated through the discourse of mechanical engineering where “good blueprints and the right instructions” abound has led to parents thinking that there could be one right way to raise a child. Bettelheim’s psychoanalytic expertise comes forth when he tells us, “[a] person is normally unaware of what goes on in either his unconscious or subconscious” (ibid:30), and that parents would like their children to perform better than they do. However applying their unconscious desire to treat their children like machines, they seek out advice which in most cases will fail. Parents “need to rid themselves of the idea that there are surefire methods which, when well applied, will produce certain predictable results” (ibid: 17). Bettelheim seems to have been able to identify the discourse of mechanical engineering. However it doesn’t seem to me that he can stand back and look at the discourse he creates through his writing. Bettelheim tells us we have “to recognize what goes on in our unconscious [...] the driving force behind our behaviour – powerful emotions such as selfish identifications, desire to retain our superiority, even jealousy [...] that often dictate our actions vis-à-vis our child” (ibid:30). How can we be helped by literature and advice that positions us, as parents, as having bad, albeit unconscious or subconscious, intentions towards our children?

We can see from the above that medical professionals have often described the standards or norms of parenthood and motherhood through their theories. We know that these theories have been widely distributed through popular literature and that their discourse has become popularized within the general public.

As parents we may find ourselves in a difficult position. On the one hand, we might find ourselves being described in unattractive ways by the medical profession, on the other hand we also find ourselves dependent on the medical profession to help us through information, specific advice, and medical treatment.

4.4. The dominant cultural discourse of medical dominance

In this section I discuss the dominance of medical discourse. This inquiry into the medical culture turns the tables on the medical profession. We are more often the objects of medical or scientific research. Here I have drawn on academic literature which has the medical community as its object of study.

Reading the literature about health communication (Geist and Dreyer, 1993; Lupton, 1994, 1994/2003; Montgomery, 2006; McNamee, in press) gives me knowledge and insights that will help the restorying of the events in my life. I would like to put this into the context of how medical discourse has permeated our everyday life (McNamee, personal communication, 2012). How has it come to be that medical discourse has become so much part of our lives?

The authority and power conferred on the medical professions is to a great extent due to the status of the science in society (Montgomery, 2006: 39). Montgomery argues that positivist science which “denotes the laws by which the physical world works, laws so regular that particular details can be invariably deduced from them,” cannot apply to medical practice. Scientific approaches may inform clinical practice, and be a necessary part of medical education, but a “science of individuals” is an oxymoron (ibid: 32). She puts forward the idea that both the general public and physicians collude in the “misrepresentation” and “misdescription” of medicine, because of the “need for certainty when taking action on behalf of another person” (ibid: 39). “At the heart of the quest for certainty is a longing for control.” Both patients and doctors alike have a need for control, which is disguised as a need for knowledge (ibid: 20). What better practices than medicine or science to provide us with knowledge, which we turn into “truths” or certainties, which will provide us with an illusion of having some form of control over our lives?

Geist and Dreyer (1993) examine the medical encounter to explore “how medical science claims to be above ideology in its objectivity and value-neutrality (Waitzkin, 1979)” (ibid: 233). Lupton (1994: 59) states, “critical theorists argue that the role of the doctor in contemporary society carries great symbolic and political power and control over knowledge.” Why would we not want to use that source of knowledge in understanding what is happening to us in times of illness and personal crisis? It is therefore and simply put to recognize how we position ourselves within dominant medical discourse when we quote doctors’ advice, books on health or illness related to the particular diseases or

disabilities that we have, perhaps, in order to be more credible, trustworthy and logical.

All of the above-mentioned authors argue for the need of changing from a monologic to a dialogic stance of communication between doctors and patients. To explain the term of monologic I draw on the meaning, “the reduction of multiple voices and consciousnesses [...] to a single version of truth imposed by the author.” To engage in dialogue, “two or more contesting voices would be allowed free play” in forming a plausible story which takes both points of view into consideration (Paryas, 1993:596). Lupton (1994/2003: 113-21) describes three approaches to power relations in medical encounters: the functionalist approach, the political economy perspective, and the post-structuralist and post-modernist perspective. The functionalist approach is depicted by Parson’s (1987/1951) “sick role” that allows the patient to be exempt from social obligations and not considered guilty for his illness in return for being compliant and passive. Doctors are seen as “universally beneficent, competent and altruistic” (ibid: 7). This medical dominance “allows doctors to take control and perform the healing function” (ibid: 113-4). The political economy perspective highlights the power of doctors in providing medical and other support services, making judgements that are included in legal decisions about people, and colluding with the state to render illness “personal, individual, to direct attention away from the socio-economic conditions,” that, for instance, poverty and malnutrition may create (ibid: 117). Lupton draws on Foucault’s description of clinical examinations, as one of the “moments in which patient and doctor collude to solve the illness problem” (ibid: 119). This is one of the apparatuses of modern power, which she describes as “not a unitary entity, but a strategic relation which is diffuse and invisible [...] closer to the idea of a form of social organization by which social order and conformity are maintained by voluntary means [...] [It] is not only repressive, but also productive, producing knowledge and subjectivity” (ibid: 121). However, in spite of not belonging to the functionalist approach, “Foucauldian theory restates the assertion of classic functionalism that medical dominance is necessary for practitioners to take control in the medical encounter to fulfill the expectations of both parties, rather than being a source of oppression” (ibid: 121). Power is therefore a dynamic, a part of the relationship, and we struggle in our relationships for power as a means of defining our identities. When our identity is that of sick patient, or mother of a disabled child, we may find ourselves both wanting to be taken care of, and wanting to determine how the doctor-patient relationship should take into consideration our agency, our ability to make decisions for ourselves, and involve us in decision-making. Lupton calls this dependency on the medical profession (ibid: 127) ambivalence. She also draws on Silverman (1987), who states, “[P]ower relations are only really challenged if the impetus for more control over the encounter comes from patients” (ibid: 123). These challenges, in my experience, did not come about by sitting down with doctors and talking about how we will talk together. In my story (in Appendix A) I recount a

number of situations where I had strong reactions within the rituals of medical practice concerning Edward when I felt that the values did not include respect and inclusiveness.

Shakespeare highlights the various discourses about professionals in his book *Disability Rights and Wrongs* (2006: 191-192) when discussing parental and medical support. On one hand he states, that professionals are necessary for and placed in a position of defining needs, of defining disability and identifying the help required. On the other hand, he states that expertise, medical training and technical language is used by professionals “to control and exclude”. In the following section about some recent encounters with the medical system in Switzerland I demonstrate how the medical profession has come to control and exclude the discourses about mothers and their different children.

4.5. Recent encounters with medical professionals in the Swiss-French region

Since I started my dissertation in March 2009, I have become more attentive to the way professionals talk, and the effects that their talk has on the people they are talking to: clients or patients, or the parents of patients. The selection of stories below highlight some of the ways that professionals and others can talk about those who have some form of disability and the parents of those people. I have chosen these stories because they have taken place in the past three years in the Swiss-French region of Switzerland where I have lived almost continuously since 1980. My own experiences date back to the years between 1984 and 2000, and I had hoped that the discourse had changed since then. I use these to illustrate the need to transform the way professionals talk, which I propose is in a monologic fashion, to move towards relational practices between professionals and families who need their services.

The professionals I encountered were working within the Swiss culture and system, be it in medicine of various schools including psychiatry, but all within public education and social services. The Swiss are known to be respectful of authority, discreet and hard-working. The expertise and authority of the doctor, the teacher and the social assistant are considered similar to that of the soldier or the policeman; they should be respected and obeyed. The Swiss judiciary system does not encourage people to sue their doctors in court for malpractice; in theory one can, in practice one is most unlikely to be awarded for damage done. It is mandatory, and a constitutional right, in Switzerland for all people to be insured for medical coverage. Should a person be in financial difficulty, the canton will pay for his or her medical insurance. In Geneva, the cost per person per month for medical insurance is roughly CHF 450.- (in 2012). (The Swiss franc is equal to about 90 American cents.) People can consult specialist doctors without being referred by their general practitioner, and yet, in spite of this freedom, the practice of asking for a second opinion is frowned upon.

In the first story, a medical professor invites an audience of parents to participate in a conference on ADHD, and launches a rabid attack on them in front of teachers, who applaud. It is considered appropriate to criticise mothers. In the second story, a mother who thought her child had autism was criticized by doctors. The same doctors did an incredible turn-around after she had her child diagnosed in another country. Doctors can ensure that mothers do not get access to support and extra services for children with special needs. In the third story, the effects of the discourse about pre-natal diagnosis on the public is highlighted, and how the general public can, in turn, behave towards mothers.

4.5.1. A psychiatrist goes on the rampage against mothers

In February 2011, I attended a symposium organized together by the state department of education, the university hospital psychiatric services and the association of parents of children with ADHD (Attention Deficit Hyperactivity Disorder) in the Swiss canton of Vaud. The audience was mainly teachers; their participation had been paid, and their attendance time counted as on-going training, a professional requirement. In the early afternoon, the psychiatrist in charge launched a rabid attack on the validity of the ADHD diagnosis. He said that it was not a syndrome; it had far too many symptoms, and presented a number of arguments about mothers that had the audience believe that the ‘myth of ADHD’ was something mothers made up. On one slide, he had a list of deficiencies found in mothers of children who were supposed to have ADHD. One of these deficiencies, he said, was depression. He hammered home the idea that depressed mothers were accountable for their children’s condition. His slides were not made public. I can only rely on my notes taken during the conference. Another professor who gave the closing speech said that it was a time for mothers to become better mothers. The teachers gave him a standing ovation. This type of speech freed them from the obligation of becoming ‘better’ teachers. About a month later, Dr. B., one of the doctors who diagnoses and treats children with ADHD told me he travelled back to town with a number of parents whom he had persuaded to attend, at the cost of eighty francs per person. He said that they were dejected and apathetic. Dr. B. argues that parents should join the association and become actively involved in demanding changes in the educational system.

Lupton (1994: 55) writes about the need to “focus attention on discourse and the ways in which the use of language in the medical setting acts to perpetuate the interests of some groups over others” in order to diminish social inequities.

4.5.2. Denying diagnosis means denying provision of support services

About the same time, the secretary of the Geneva-based association for parents of autistic children told me about a situation where doctors had written glaringly disparaging remarks in a report about a mother’s way of raising her child, whom she claimed was autistic. The doctors refused to assess the child to confirm the diagnostic. The mother took her child to another country for testing and

returned with a diagnosis of autism. Several months later, she received a copy of a report written by the same doctors for the Assurance Invalidité (Swiss federal disability assurance), claiming that she was a wonderful, attentive mother. The association secretary said that denying diagnosis was also a way of denying support or ensuring appropriate services; it was, therefore, a political issue. One of the things I find interesting in this story is that the local doctors actually accepted the diagnosis made in another country and awarded the mother access to the support services. This mother did not defer to the local medical opinion, and took the decision to consult elsewhere. Here is one story of resistance to medical dominance (Lupton, 1994/2003: 123).

4.5.3. The influence of medical discourse on our own opinions

In September 2011, I attended a conference organized by Pro Infirmis, the largest non-profit organisation for the defence of disabled people's rights in Switzerland. The conference was organised for the public-at-large to provide them with information in view of the upcoming federal governmental debate about the legislation of pre-implantation diagnosis of embryos, which could lead to an amendment of the current federal law on medically assisted procreation. As the day advanced, each professional speaker told us of the effects that the new law would have on the way disabled people are regarded in Switzerland. The chilling message was that there is a strong possibility that if the public believes that there are medical ways to avoid bringing disabled people into this world, that the public's tolerance towards disabled people could be reduced in the future. The same day over the supper table, my friend's 90-year-old mother-in-law told me that she saw a woman in the village with a young child who has Down syndrome, adding "that really in this day and age, you would have thought that that kind of thing would no longer exist." In her view, the mother of this child should not be given financial support from the state as she should have taken steps to avoid giving birth to the child.

4.5.4. Reflection on the values and beliefs embedded in discourse

These stories indicate some of the values and beliefs held by professionals that become embedded in our everyday discourses. Below I list my interpretation of these values and beliefs. Perhaps you found other meanings.

The mothers whose children have learning difficulties or disabilities have passed them on genetically, or caused them through their parenting behaviour.

The doctors can criticize mothers for their actions and infer that the children would be better off without such mothers.

The teachers do not have to provide special assistance to children who do not fit into the current educational system.

The healthcare system can continue to delay assessments and, thereby, refuse support services to mothers.

The mothers should not request costly support or special services for themselves or their children from the state when they could have avoided giving birth to handicapped children.

4.6. Research on the effects or experiences of mothers with different children

In this section I introduce an overview of academic and medical literature on the experiences or effects of mothers and parents with children who are positioned as being different. The purpose of this section is to highlight the body of knowledge and research that exists on the subject that neither, in my experience, seems to be reported nor does it seem to influence professionals when dealing with mothers. There are examples of medical literature on supporting parents through counselling and other interactions with professionals, and I present one at the end of this section.

4.6.1. Introduction

An overview of academic literature on the subject of mothers with children who have some form of intellectual and learning disabilities demonstrates how often the subjects of maternal well-being and parental or maternal stress are mentioned. Variables studied include the possibilities of employment, their socio-economic position, the household composition, the school ages and other indicators (Stephenson, 1992; Dyson, 1996, 1997; Cigno and Burke, 1997; Shearn and Todd, 2000; Hastings and Taunt, 2002; Johnston, Hessel, Blasey, Eliez, Erba, Dyer-Friedman, Glaser, and Reiss, 2003; Emerson, 2003; Bromley, Hare, Davison and Emerson, 2004; Emerson, Hatton, Llewellyn, Blacker and Graham, 2006).

According to Johnston et al. (2003) it has been well documented that the parents of children with intellectual disabilities, learning difficulties, developmental delay, are more likely to suffer from psychological stress than the parents of “typically developing children” (ibid:267). Mothers are more likely to experience stress related to childcare, in spite of progressive changes in the distribution of parenting responsibilities between mothers and fathers, because mothers continue to carry the disproportionate burden in raising a disabled child. They demonstrate “depression, anxiety, health problems, social isolation and low self-esteem (ibid: 267). Dyson (1996) found that parents with children with learning disabilities experienced greater stress than did parents of non-disabled children. In addition to problems of sibling relations, the families experienced adaptational difficulties especially with regard to the school (Dyson, 1996). Stephenson (1992) found that mothers of children in learning disabilities classes showed high levels of frustration and dissatisfaction with the services provided by educational and mental health professionals. Their

expectations and perspectives differed from those of the educators. Cigno and Burke's (1997) study of single mothers of children with learning disabilities found that the mothers were affected "by the lack of partner support, availability of transport and fears for the future. These issues often led to a degree of isolation for the family as a whole." The authors propose a "sympathetic, integrated approach by professionals to their family situation." Bromley et al. (2004) reported that the majority of mothers with children with autistic spectrum disorders reported high levels of psychological distress associated with low levels of family support and with raising a child with higher levels of challenging behaviour. The study also investigated areas of useful support including care breaks and advice. Shearn and Todd's study (2000) focuses on the perspectives of employment for mothers with children with intellectual disabilities. Mothers, in the study, reported feeling that their employment possibilities were reduced due to the societal expectations of mothers, especially mothers of children with disabilities. For those in full-time employment their stress was higher due to the demands of both work and home, and from a fear that they were failing as mothers. Emerson (2003) reported that children and adolescents with intellectual disabilities were more likely to have particular psychiatric disorders. Emerson et al. (2006) reported that mothers with children with intellectual disabilities are more likely to show signs of psychological distress and have lower well-being than mothers of 'typically developing' children. Socio-economic disadvantage played a greater role than any other indicator in the mothers' reduced well-being. Dyson (1997) reported that parental stress was associated with aspects of family functioning as perceived by the parents themselves.

I have extracted these studies to show the variations in focus of study around mothers with children in difficulty. I will not report on the psychological indicators used in some of these studies, as I do not want to advocate the medical model of looking at mothers in a way that highlights mothers' individual weaknesses as if they were essentialist.

The first thing that strikes me, and that might impress you, is the amount of knowledge accumulated through these studies on mothers with children in difficulty. Children in difficulty often have mothers who are in difficulty associated with the practices of rearing a child with a difference. There are correlations between the associated factors, which do not constitute proof of causal relationships (Johnston et al., 2003). Lack of family income or lack of maternal employment possibilities affects the socio-economic wellbeing of a family (Emerson et al., 2006). Lack of transportation affects getting children to school, and creates a sense of isolation. External factors certainly can play a great part in affecting parental wellbeing, but the expectations of the right way of family functioning can be internalized and lead to self-deprecation (Dyson, 1997). Hastings and Brown (2002) report that there is a high risk of mental health problems, in particular anxiety and depression in mothers of children with autism.

The second thing that strikes me is the lack of distributed knowledge amongst those professionals who can make a difference. I wonder whether it is because these studies are in journals related to mental retardation, intellectual disabilities or autism, and not in journals related to medicine or paediatrics. I have argued before about the dominant medical discourse, the medical model and how it influences societal discourses. It seems that we have an opportunity to inform the medical population of this body of research about the parental stress in regards to the difficulties of raising a child with an intellectual disability or difference which seems to go relatively unreported. These various studies are demonstrations of a discourse that claims that mothers with children in difficulty have greater challenges in raising such children than parents of non-disabled children. Such mothers and parents can also come under the magnifying glass in that they are studied and critiqued in the way they support their children. I will discuss the methodology in Chapter Six.

4.6.2. Parental support of different children

Shakespeare (2006: 187-188) writes that he was amongst the proponents of the argument in the late nineties that parents and families were not providing the idealized unconditionally loving and nurturing caregiving, and that homes could also be places of abuse. The dominant discourse, prior to that, stated that care provided in the family homes would be better than in institutions for people with impairments/ disabilities. In this way, “society relied on families to provide unpaid care,” which he says can ruin relationships. He writes, “[M]ore recently, writers on mental health have shown how parents are part of the problem for many people who experience mental illness.”

He quotes Avery’s (1999) studies of parents’ ‘tragedy’ stories and her findings that parents’ experience has not had much attention paid to it, in part because of the ‘socially derived guilt of shame attached to disability’ (Avery, 1999:117). Shakespeare writes, “there might be a danger of ignoring or undervaluing the role of parents. In stressing the negative aspect, there is a danger of giving an unbalanced picture, and failing to see all the good and hard work which parents of disabled children do. Parents are almost always the primary carers of disabled: they help them through encounters with doctors and hospitals; they support them through education and try to enable them to make a successful transition to adulthood. Parents also suffer when they see their child suffer” (Shakespeare, 2006: 188). Shakespeare draws on other researchers (Harden, 2005; Aitkin and Hussain, 2003; Bjarnason, 2002; Goodley, 2003) who highlight the work of parents, but also the ambivalence around the role of parents. While parents can be advocates and sources of strength, they can also be seen as “unable to let go, as being over-protective” (Shakespeare, 2006: 189).

4.6.3. Support from mental health services

Sandra Baum writes, in *Intellectual disabilities: a systemic approach* (2006), how the treatment for patients with mental health needs is invariably decided by the health services for many people with intellectual disabilities, when their needs are not denied or unacknowledged. She reports that this group of service users rarely had someone to listen to them and help them make sense of important events. She writes, “It is perhaps, therefore, unsurprising that [the services] have been slow to respond to the emotional needs of the families and the carers” (Baum, 2006: 27).

Glenda Fredman (2006) writes that family members frequently refuse to attend sessions for fear of being blamed and criticized for the problems associated with the person with intellectual disability. She writes that some families reported being labelled “mad” or “bad” by professionals.

Epston (1999) writes that family therapy and practice in the late 1980s had become “at worst ‘family-blaming’ and at best ‘family suspicious.’” Narrative therapy arose out of his determination to find an alternative compassionate frame of reference.

4.6.4. An example of medical advice on counselling parents

The paucity of research on counselling parents with children with disabilities (Luterman, 2004) could possibly be read as a lack of interest in the counselling of parents to deal with their children. However, one article about the counselling of parents of hearing-impaired children during the post-diagnostic period by Schmanman and Straker (1980) grabbed my attention as an example of useful literature for its emphasis on supporting parents through counselling. The authors argue that professionals who are in contact with the newly diagnosed child and his or her parents should be trained to deal with the parents’ emotional reactions. If the way a child learns to deal with his or her inability or disability in hearing is to a great extent facilitated by the way the parents support him or her, then helping parents is an important part of the remedial care. Clinicians, including teachers, are, they propose, the right people to be “parent counsellors” (1980: 252). Parents have reported that their need for help was greatest at the time of the diagnosis (ibid: 253). Although parents were dealing with their child’s way of being before diagnosis, there seemed to be a shift into a crisis-like situation when the diagnosis was given. The authors write, “The family’s reaction depends on the structure of the family itself, its crisis-meeting resources, and its ability to cope with stress on a long-term basis. No two families will react in precisely the same way” (ibid: 252). The authors propose that support and help should therefore be provided based on the individual situation and needs of the family.

4.6.5. Conclusion

In conclusion I would like to propose that it would be easier to devote time and effort into working in partnership with children, parents, teachers and other professionals in order to find ways of helping the children. There is sufficient research to show that mothers and parents are in need of support.

As a social worker said to me in May 2012 when I was attending a one-week course in Narrative therapy applied to family situations, “if we want to help the children, we have to support the parents.” From this chapter, I think that it is clear how much time and effort these mothers have put in to assist their children. It would seem that sometimes their work has been made more difficult by the insensitive remarks of the professionals and other mothers. A positive sense of self, fuelled by encouraging remarks and practical support, would be much more helpful to these mothers. In the next section I describe the potential effects, or experience, that mothers may come to know intimately when their children is different, when doctors and other professionals believe that it is the mothers’ fault, and when support is denied.

4.7. The potential effects on mothers: guilt and shame

“People know what they do; they frequently know why they do what they do; but what they don’t know is what what they do does.” Foucault quoted in May (2006:19)

As within all dominant discourses, there are some people who are empowered by them, and some who are disempowered. I would argue that mothers are disempowered by the medical dominance largely for two reasons; the first is that generally difficulties and illness are constructed as personal and individual, which can confine mothers to isolation. And secondly, a history of “anti-mother” discourses has left its indelible mark on the medical profession (Lupton 1994/2003). Lupton writes, “An earlier study of the discourses on maternal behaviour in textbooks and newsletters written for paediatricians in the 1970s (Hovell, 1978) [...] found a strong tendency for paediatricians to describe their work as ‘rescuing’ children from those who would harm them. Parents were singled out in particular, and mothers disparaged as contributing to the ill health of their children through neglect or ignorance, or on the other hand for being unduly alarmed over minor illness (1978:204)” (ibid: 166-7). My experience is that mothers’ voices have been not been heard in Switzerland, which may partly be due to our customary discretion, which tells us that we do not talk to others about our problems, and we do not inquire about others’ problems and difficulties. My Swiss husband questions whether it is really discretion. He says, “we observe others through the crack of closed curtains at the window in the comfort of our homes.” I would also argue that women have yet to realize the benefits of telling their stories collectively, which would bring about change in both medical and educational practices.

During my inquiry, I interviewed five mothers with children diagnosed with ADHD, and heard many talk about feelings of shame and guilt. One of the mothers, Hélène, told me of a doctor in the Lausanne area who says that the parents of children with learning disabilities or other disabilities should be applauded for the immense job of parenting that they do. And yet talking to these mothers, the shame or guilt that they experience that seems to cling to them. In February 2011, I attended a Narrative Therapy training workshop entitled *Social Context, Discourse and Power*, which introduced me to Jenkins’ (2009) work. I also researched the literature of traditional psychology and sociology to understand more about guilt and shame (Lewis, 1993; Niedenthal, Tangney and Gavanski, 1994; Scheff, 1997; Tracy and Robins, 2004, Tangney and Dearing, 2002; Gilbert and Procter, 2006). It was a time of discovery for me personally, as I found alternative stories, or ways of understanding our cultural practices. In the following pages, I draw on academically-based psychological literature to describe these notions. I have said elsewhere that it is useful to draw on such literature because the authors have reflected upon the notions of guilt and shame. However, I do not adhere to the essentialism that the authors often apply to these notions. We may all seem to write about something experienced first-hand as if it were a universal truth,. Writing about

experiences that I have personally experienced sometimes leads me to feeling that I am gripped within the grasp of these strong feelings, overwhelming me and luring me into believing that this is enduring and consistent. You may find that I am equally responsible for writing what you could evaluate as an essentialist perspective.

4.7.1. Inquiring into the literature on guilt and shame

Guilt and shame are potential effects, or experiences, on people who do not live up to the normative expectations embedded in discourses about them. Giddens (1991: 64) writes, “Guilt is anxiety produced by the fear of transgression: where the thoughts or activities of the individual do not match up to expectations of a normative sort. [...] [G]uilt concerns things done or not done. [...] [I]ts prime emphasis tends to be on discrete elements of behaviour and the modes of retribution that they suggest or entail. Niedenthal, Tangney and Gavanski (1994) describe guilt as concerning an act, a behaviour. Lewis (1993: 624) says that most people evaluate their level of responsibility for an act, and if they consider that they are not responsible, they stop feeling guilty. Guilt is seen as a more adaptive behaviour, because it makes people feel remorse or regret and take reparative action.

Giddens (1991: 65) writes, “Shame bears directly on self-identity because it is essentially anxiety about the adequacy of the narrative by means of which the individual sustains a coherent biography. [I]t is stimulated by experiences in which feelings of inadequacy or humiliation are provoked.”

It is interesting to see how the descriptions of shame and guilt are written up. I wonder why is it that psychologists have to go to such lengths to tell us what shame and guilt are like, what effects they have on us and other people. It is a good example of social construction. These feelings are not being solely described, they are being constituted by such writings. McNamee says to “locate ‘guilt and shame’ as plausible performances in the face of an incoherent narrative is a more fluid understanding than to locate them as properties of people” (McNamee, 2013, personal communication). Niedenthal, Price Tangney and Gavanski (1994: 587) question whether the participants in their research, “verbal, well-educated young adults”, could distinguish between shame and guilt as they used them interchangeably. They also referred to different situations eliciting these emotions. Lewis (1993: 623) points out that the study of these “self-conscious emotions” has been neglected for various reasons; one of them being that it is realized “that there are no clear, specific elicitors” for such emotions; they cannot be linked to specific events. Tracy and Robbins (2004: 107) state, “self-conscious emotions do not have discrete, universally recognized facial expressions”. Contrary to the universally recognized, facial expressions of joy, anger, sadness, surprise, disgust and fear, psychologists cannot read, recognize and categorize self-conscious emotions. It seems to me to be a legacy of Freudian psychodynamic practice that experts should want to identify characteristics of people without them, i.e. the people,

being aware. However, in spite of these descriptions and studies, there are phenomenological descriptions of shame that resonate, which shows the extent of how constructs are created relationally. It seems that even these psychologists have a personal understanding of what “shame” can have as effects on a person. Tracy and Robbins (2004: 108) write, “Shame is such a self-damaging and painful emotion.” Lewis (1993: 629) writes that shame leads to “confusion and to the loss of action.” Gilbert and Proctor (2006) write, “Shame [...] seems to have a certain ‘stickiness’ about it, which can easily pull individuals into a ruminative, self-critical style, increasing vulnerability to a range of difficulties.”

Shame is undoubtedly social. Schneider (1977:28) writes that to feel shame “implies that a person cares” and values the other person. We care about other people’s views of us. Perhaps because we learned to care when we were young, that doing something against our care givers’ wishes might elicit a reprimand or a temporary withdrawal of love and affection (Giddens, 1991:64).

Munt’s (2007) work, *Queer attachments: The cultural politics of shame*, delves into “shame as a socially constructed and historically contingent entity, [or] system” which can construct people as subjects. She writes that shame has become attached to normativity as a process that upholds it (Munt, 2007: x). It would seem important to investigate the construction of shame as a process that holds mothers accountable for achieving the cultural standards and norms of motherhood. These standards and norms also constitute the moral orders, or the discourses, that abound.

Tangney and Dearing (2002: 2) write that shame and guilt are emotions that are both self-conscious and moral. “Self conscious in that they involve the self evaluating the self, and moral in that they presumably play a key role in fostering moral behaviour.” Schneider (1977:18) writes of the two uses of shame, which are linked to moral behaviour, one being “the disgrace” we can feel after an act, the second being “discretion,” which hinders us from taking action. He writes that other languages, like French, have words to depict these two uses that we do not have in English. In French, for example, there is “honte” for shame-disgrace and “pudeur” for the shame-discretion he describes. In French, “pudeur” is described as the “apprehension of what could hurt decency; a sort of modesty or discretion; a refraining that stops one from saying something, hearing something or doing something that may cause embarrassment”(translated by myself from the iPad application Littré, a French dictionary).

I find myself asking why is it that the women I interviewed talk of their ongoing guilt and shame-disgrace in spite of all the incredible actions that they have undertaken. It is as if the child’s difference was something that they were responsible for, even when they knew or were told that they were not. In Genevieve & Margulies’ study, mothers whose children were different, and in difficulty, “were plagued by a nagging feeling of guilt, a guilt that was not assuaged by the fact that, deep down, they knew they were not responsible for

their child's affliction" (Genevie & Margulies: 261). One woman is quoted as saying, 'The doctors have told me that my child's birth defect is not my fault, but I cannot help but feel that since I carried this child in my body that it is [...] I find myself thinking about when I was pregnant with her, trying to figure out what I did wrong' (ibid: 261).

I too suffer from guilt as I have already told you. That guilty voice inside of me that tells me I didn't do enough because Edward was not diagnosed until the age of sixteen. This voice holds me responsible for not doing enough. The following is an account of what that voice was capable of pushing me to do.

After Edward was diagnosed with ADHD at the age of ten and Ritalin did not have the "desired effect" I took Edward to a kinesiologist who reminded me of a faith-healer when he laid his hands on Edward, and did a number of exercises, none of which he explained. I have taken him to a conference where the visiting French professor in osteopathy claimed that children born by C-section needed to have their cranial structure re-aligned, and used Edward's head to show his audience how to manipulate the head to re-align the structure. I have taken him to a man who promised to restore his body's energies with a machine that looked something similar to the machines one hooks up to a car battery to recharge it. I have taken him to a naturopath who prescribed spiruline, and other natural medicines, that would expel the metal toxins from his body, that cause ADHD. Years later, another naturopath said to me that that treatment was wrong; it actually made the metal stay stuck in the brain and cause dementia in later years. I could only hope that Edward had not taken the medicine when he was at boarding school, as I sometimes suspected.

My guilty voice incited me to turn to alternative treatments when the traditional, medical treatments didn't deliver on their promises. To request treatment from a traditional practitioner or an alternative practitioner, is to place some amount of faith in them, and when their treatment does not work, one wonders why one invested so much energy, so much time into something that does not work. After Edward's diagnosis, this feeling of insecurity and fear of having hope continued. When reading about hormone substitution in the medical research on Klinefelter syndrome, we found one article that described the increase of self-esteem and wellbeing for "most" patients. My husband said to me, "Don't get your expectations up. With our luck it won't work on Edward." And that became a regular saying for us. Whenever we read medical literature that indicated that a form of treatment could help Edward, we would say to each other, "No expectations." Today, Edward's medical treatment is facilitated by an empathetic endocrinologist, Dr. P.M., and the nurse practitioner, Mrs. P., at the Geneva University Hospital. Perhaps I am telling you this to reassure you that today he has access to treatment that helps him.

Perhaps I also should introduce you to another one of my voices, my "fuck-you attitude" voice, which blames particular doctors for not either diagnosing Edward earlier, or not wanting to seek a medical explanation for his difficulties.

This voice is perhaps also one that was constructed in relationship with these doctors. One of the doctors told me to stop wanting to turn my son's difficulties into a medical problem. Claudia Malacrida writes, in her book *Cold comfort; Mothers, professionals, and attention deficit disorder* (2003) about "the broken trust mothers experienced when professionals proved themselves to be fallible and the invasive procedures that had been for naught. Hence, mothers expressed an obvious sense of betrayal when professionals clearly failed to deliver on their promises of care and solutions. In addition, however, because they had been too trusting of professional knowledge claims despite the obvious weakness in professional practice, and –reflecting common understandings of what good mothers should do – because they themselves they should have known better and sooner what their children's problems were" (165).

Scheff (1997) writes that pride and shame control social bonding. "Pride signals and generates solidarity. Shame signals and generates alienation" (Scheff 1997: 74). Evison (2006) describes the behaviours of "aggressive, sarcastic, or judgmental remarks applied to others or to self" and draws on Scheff's (1997) claim that socialisation of shame expressiveness forms the basis of destructive anger and conflict. It would seem that this explanation is helpful in depicting the correlation between the negative remarks made to mothers about their mothering and the anger that mothers can express towards themselves and towards others. Negative remarks, or put-downs as Evison (2006) categorises them, made by people in positions of status and knowledge are perhaps more damaging than those made by someone we do not care about. We do, very often, care about the expert's opinion. This appears as a form of modern power, whereby the expert positions the other in a way that blames or victimizes the other.

Tangney and Dearing (2002) write, "shame-prone individuals appear relatively more likely to blame others (as well as themselves) for negative events, more prone to a seething, bitter, resentful kind of anger and hostility, and less able to empathize with others in general" (4). It is interesting to note that shame and anger are so entangled. Sampson (2008) states that anger is not so much an inherent quality as a reaction to life, in his example of angry black youth in the United States. He writes, "... to suppose that 'anger' is a property of 'black youth,' [is] to miss the very real social processes by which the 'black male' is made angry and kept angry by social policies that create the very conditions of hopeless living that would make any person feel rage" (27). How would other people feel if they were submitted to the same discourse that mothers are submitted to? In the story about the ADHD symposium, Dr. B. recounted that fathers, not just mothers, were dejected after the event. It would be interesting to look at the situations where fathers are present in medical encounters about children in difficulty.

Hélène, the president of the Swiss-French association for the parents of children with ADHD, the ASPEDAH, tells me that it is difficult to have mothers with that kind of attitude on the committee or working as volunteers in certain

positions. When working with doctors, it is not helpful to have that attitude because it offends the doctors and alienates them. However, she says, it is useful to have a certain amount of anger-energy when working with parents who have become apathetic. From her point of view, and my own experience is that, such an attitude decreases as time passes and/or as a parent sees his or her child succeed in socially-acceptable areas of life.

My personal experience is similar to the descriptions of shame. Shame grabbed me after Edward's diagnosis of Klinefelter syndrome, and consumed me. I remember pummelling my belly and blaming my body for having given Edward this chromosomal disorder. Dr. J., a well-known paediatrician and advocate for children with disabilities, told me in an interview on March 7, 2011, "You are not responsible for your genes." That is not how I felt. The shame I felt made me avoid paying attention to what was happening. Paying attention may have involved being subjected to further scrutiny and evaluation. When writing my story, I paid attention to reports and documents that I had not paid attention to, that I had been confused about, and I could finally pay attention to. Through the interviews with the mothers, I came to understand how much I have been involved in the performance of shame, and that to listen to other mothers' stories was equal to finding a sisterhood.

The medical discourse informs and colludes with dominant discourses of motherhood in the Western world, which situate mothers in the midst of modern power practices. Not only are the normative expectations of mothers dictated, but those of the children as well. With children who are in difficulty, like those who have been diagnosed with ADHD, mothers are doubly blamed, once for having a child who does not behave 'as is expected' in public, and secondly for 'being a bad mother'. In one of the interviews, Helene said, "When a child has inappropriate behaviour in public, everyone looks at the mother, of course, as if she wasn't doing anything to control the child."

In my interviews, I invited mothers to tell me about messages or remarks that they heard from anyone that were helpful to them as mothers, and those remarks that were not helpful and how they reacted to them. In this way I heard a wide variety of discourses and their effects on the mothers. One mother described how she would get down on all-fours to clean up after her son at the playschool he attended, and how she could sense the other mothers and the teacher laughing at her. When her son attended primary school, she avoided all contact with the teacher and other mothers, becoming a 'social recluse'. One mother quoted some research that claimed, "80% of all ADHD children who are not treated medically end up as delinquents". Although there were still signs of anger and frustration, fear and sadness, there was a general sense of resignation that little could be done to 'educate' professionals (educational psychologists, speech therapists, doctors, nurses, etc.) and family members and friends about the effects of the discourses upon these mothers. Those mothers who had found solutions for the school difficulties, generally considered the most demanding, or whose children had finished school were less anxious about their children's

future. Four of the mothers were committee members of the Swiss-French association for parents of children with ADHD, and as they discussed their experiences of talking with me, they chose to talk of ‘oppressive social pressures’. It seemed to me that they, too, experienced their guilt and shame as something personal and individual, which required individual solutions, not political or social reforms.

Giddens (1991: 66) claims that, “the other side of shame is pride, or self-esteem.” It would seem to me that it would be in everyone’s interest for mothers to have a positive sense of self when raising our children.

4.7.2. Treating shame

If we continue to consider shame and associated feelings as individual pathologies unrelated to the reality of the people concerned, then it seems to make sense how traditional psychodynamic therapy finds them so hard to treat (Gilbert and Proctor, 2006: 354; Tangney and Dearing, 2002: 175). Gilbert and Procter (2006) claim the shame-affected population can find notions of self-warmth and self-acceptance difficult and/or frightening. Their ‘Compassionate Mind Training program’ is similar to Cognitive Behavioural Therapy, a highly evaluative approach that maintains constant self-evaluation, but with the difference of teaching mindfulness techniques.

Tangney and Dearing (2002:176) recommend humour as a way of working against shame. As the late French comedian, Pierre Desproges said, “On peut rire de tout, mais pas avec tout le monde.”⁵ » (You can laugh about everything, but not with everybody). I would argue that it might be alright to use humour in some instances, but as a doctor once pointed out to me, my use of humour or my ability to joke or laugh in crisis situations with my son has led others to believe that I had sufficient resources to cope, that I was not either desperate enough, or not humble enough to deserve support.

4.7.3. Mistaken shame

I came across the notion of “mistaken shame” in Jenkins (2009) as being distinct from ‘disgrace-shame’, which is experienced as a result of dishonourable or unethical actions. He explains that disadvantaged men have not committed such actions, but that through ‘politics of disadvantage’ people with more privilege or power attribute shame to them, for not having achieved socially expected success, for being a ‘failure or loser’, which makes them feel worthless and guilty, personally responsible. Jenkins states that, “shaming others is a political act” (Jenkins, 1009:20). I would argue that mothers often find themselves positioned through ‘politics of disadvantage’ by others with more privilege and/or power. This is an example of modern power.

⁵ Retrieved from http://fr.wikipedia.org/wiki/Pierre_Desproges on June 8, 2012

Feeling a “failure”, not living up to the norms and expectations maintained through practices of modern power (White, 2005) in dominant cultural discourses, is a frequently encountered phenomenon in therapeutic conversations. Addressed by various maps (or conversational practices) in Narrative Therapy (NT), one of the goals is to deconstruct the discourses to “reveal the hidden assumptions behind these taken-for-granted truths; and which reveal who benefits and who loses from these assumptions” (White, quoted in a course hand-out, Institute of Narrative Therapy, United Kingdom).

Narrative therapy is criticised for holding a social constructionist belief that there is no absolute truth; no moral tone; “that anything goes”, and thus people are not held accountable for their acts. Jenkins’ work shows that there is indeed an ethic of accountability within this field, and that the practice of ‘externalizing the problem’ is not used in such a way as to allow men who have abused, for example, to dissociate themselves from their unethical acts and their effects.

By not considering the dominant cultural discourses and normalising judgements that influence people and are maintained by people, modernist psychology avoids the opportunity of deconstruction and maintains the practices of modern power.

4.7.4. Conclusion - finding my voice of “mistaken shame”

Perhaps I will be able to transform that angry, difficult voice into an enlightened voice of mistaken shame, when I tell my story of how it was that I found myself in the midst of modern power practices, held responsible for raising a child, in difficulty, with an undiagnosed genetic syndrome. It seemed to me that by deconstructing the dominant discourses and the practices of modern power of ‘motherhood’ discourses, I might not only diminish the power and the clamouring of my inner voices, but also assist other mothers in doing the same, and perhaps more daringly become politically involved in the defence of mothers. I draw on Jenkins who writes about being able to identify and name the power relations which have determined that an individual or a group should be made to feel shame for not living up to the normative, “unhelpful cultural and gendered expectations” (Jenkins, 2009: 23) so that we might bear the responsibility of raising children like Edward. He says our “ethical challenges” should look at assisting those in need in renouncing mistaken shame, facilitating a sense of their social inclusion and belonging, and finding enabling ways to address their own tendency to assign blame and shame to others.

In summary, I have defined medical discourse as being primarily one of dominance, in which the power dynamic within the relationship between doctor and patient is, for historical and local reasons, difficult for patients, or mothers of patients, to negotiate. I have described my own and the mothers’ experiences of feelings of guilt, shame and anger as being partly due to the effects of that power dynamic, or modern power practice. I have presented various

formulations of these “self-conscious emotions” and their treatment. I argue that the attribution of blame and shame is political, that it serves the interests of a privileged group to hold mothers responsible for their children.

Chapter 5: Stories about different children and their mothers

In this chapter, I would like to discuss the two medical terms used to describe and explain my son's differences. In Chapter One, under Point 1.4., I explained why I have included the two differences, Attention Deficit and Hyperactivity Disorder (ADHD) and Klinefelter Syndrome, in this dissertation.

My son was diagnosed with ADHD in September, 1995. In December 2000, he was diagnosed with Klinefelter Syndrome. Neither difference has bodily markers in childhood. Klinefelter Syndrome is often diagnosed when the boys should be experiencing puberty. One of the commonalities, in my experience, is that when there is no diagnosis, or when a diagnosis is disputed as is the case of ADHD, it is the mother's parenting that is called into question. ADHD is a site of competing and conflicting discourses, and involves a conflict of interests and positions between various groups of interested and/or concerned people. It is within this site of conflicting discourses that motherhood is contested and framed by cultural dominant discourses.

In the first part of this chapter, I discuss ADHD and relate the stories of the mothers who participated in my inquiry. I have outlined the method of narrative inquiry and questions in Chapter 3 under Point 3.8.4. I interviewed five mothers of children with ADHD. The stories were published (Lindley S., 2011) and the interviewees are known by the fictitious names of H  l  ne, M  lanie, Marie-Jo, Karine and Marion. My primary goal in interviewing these mothers was to inquire into how they had dealt with the discourses that they found themselves embedded in, and to hear about those discourses. In the first section of the accounts of the mothers, I recount the stories that pertain to ADHD. In the second section I recount the stories that demonstrate their insertion within the cultural dominant discourses that they negotiate. I have highlighted their names so that you can follow the five mothers' specific stories. My stories are in *italic*, and were not included in the book (Lindley S., 2011).

In the second part of this chapter, I discuss Klinefelter Syndrome, which is categorised as a Variation, formerly Disorder of Sexual Development, or an intersex condition.

5.1. Motherhood of different children

To be the mother of a child who is different is experienced in different ways by all the mothers concerned. Sometimes it is helpful to read psychological studies that provide us with the most often related experiences, but not always. I find myself constantly within the dynamic tension of wanting to believe something

that corresponds to my lived experience as being a truth, like the literature I presented in Chapter Four, Point 4.6., and wanting to place a warning on all such papers, that reminds the readers that their experience could be like this, but it is possible that it is different. You may experience my writing denigrating modernist, structuralist forms of psychology, but I sometimes feel angry for their insistence on being experts and presenting a discourse, which so often excludes the voice of mothers. However, I do find it extremely helpful to read modernist psychological accounts because there are ways of presenting information, which can be drawn upon. As I have already written about shame in Chapter Four, you can see how reading about other people's ideas and experience can widen our own knowledge and understanding.

In Chapter Four I have written about the discourses linked to motherhood, and to some extent how mothers have to negotiate their identities within the culturally available discourses, particularly within the dominant medical discourses that have permeated society. In this chapter I am addressing two types of difference that some children have, and which have different associated motherhood discourses. It would seem that there is a relatively substantial percentage of the population who have differences. In an American study, Genevie & Marolies (1987: 257) reported that the prevalence of mothers, in their study, whose children had "serious problems" was twenty percent. Although the problems reported were different, the authors state that the mothers' difficulties were "strikingly similar" in part because the brunt of the situation usually falls on the mother. Roughly ten per cent of the mothers had children who were diagnosed with a serious illness or a disability.

Solomon (2012) writes about parents whose children are born different, using the metaphor that they have "fallen far from the tree," as opposed to close to the tree, which infers that a child resembles his or her parents. Solomon's theory is that parents have children in order to perpetuate themselves, and that a different child does not continue the "transmission of identity from one generation to the next" (Solomon, 2012: 2). He says, "these children are apples that have fallen elsewhere – some a couple of orchards away, some on the other side of the world," and are "not what [the parents] originally had in mind" (ibid: 5). This notion of "selfish gene" is a singularly individualistic approach, which places the difficulty of acceptance on a personal level, and seems to ignore the societal pressure to have a child who conforms to the norms and expectations. His argument is that "myriad families learn to tolerate, accept, and finally celebrate" their children's differences. From the following stories, you will see that the mothers accepted their children's differences until they were told that their children were not tolerated or accepted by others.

5.2. The site of conflicting discourses of Attention Deficit and Hyperactivity Disorder (ADHD)

5.2.1. My personal interest revived

My active interest in ADHD started with Edward's diagnosis in 1995 and ended when he was diagnosed with Klinefelter syndrome in 2000. Talking to the mothers in the summer of 2010 revived my interest, and it increased after attending the symposium in February 2011. I present a story from the symposium in Chapter Four under Point 4.5.1., where a professor of psychiatry of the Cantonal University Hospital of Vaud denied the existence of ADHD arguing that there were too many symptoms for it to be one syndrome, and stated that a major cause of children's difficulty was their mothers' depression. In July of the same year, I attended a conference for the medical professionals given by Dr. Russel Barkley, a renowned American ADHD specialist and advocate in Lausanne in July 2011. At the break time, I went to talk to Dr. Barkley about the lack of recognition of ADHD by the professor (who was attending the same conference). He said that it was a common phenomenon that he had experienced in the European Nordic countries as well, that the medical professionals had to be convinced that it was not the mothers' upbringing that was at fault, but that the disorder actually existed. He reminded me that autism had also been originally blamed on mothers. A quiet-spoken, compassionate man, Dr. Barkley reminded us when showing the powerpoint slides full of statistics, that "statistics are actually people whose tears you can't see" (Barkley, 2011, conference slides).

Following Edward's ADHD diagnosis I had many e-mail discussions with my friends, Rose and Richard, which you can find in the appendix A. Richard encouraged me to read *Talking back to Ritalin* (Breggin, 1998) and my mother sent me *Creating kids who can concentrate* (Robb & Letts, 1997) and I purchased *The hyperactive child: A parents' guide* (Taylor, 1985/1994). These three books do not question the existence of ADHD, but encourage parents to find other ways to help hyperactive children or children who cannot concentrate. Taylor writes, "Hyperactivity leads to real problems with personal adjustment. It can sometimes be difficult to know exactly what the problem is, but it is usually quite clear that a problem exists" (Taylor, 1985/1994: 15). I agree with Taylor's words. A problem does exist, but the problem is not situated 'within' the child, or 'within' the mother. The problem exists within society where children who are positioned as being different are rarely appreciated for that difference. Rather than perpetuate the belief that there is something wrong with the children and/or the mothers, I have found that it is both more respectful to mothers and children to talk about them as being in difficult situations, and it is easier to look at solutions if we talk of situations being problematic rather than people being problematic, in the sense of White's notion of 'externalising' the problem (2007).

5.2.2. Social constructionist perspectives on ADHD

Gergen (2010) has written about Attention Deficit Disorder, a variation of ADHD, saying that there is “nothing inherently ‘ill’ [...] with a highly active child. Nor is the child itself in a state of anguish.” Gergen argues that the label results from a combination of influencing factors: teachers’ inability to manage such children, psychiatrists’ willingness to define mental illness, and the pharmaceutical industry’s profits. Elsewhere he questions (Gergen, Cisneros-Puebla & Faux, 2008) whether the labelled child has “been ‘treated’ or ‘victimized’” because “he has a ‘disease’ which will always be threatening him, or so he thinks.” From the stories in this chapter, I think that you will understand how the child can suffer through practices of exclusion in pre-school and school activities, and that as Shakespeare (2006) says, many parents suffer when their children suffer.

Malacrida (2003) has written about mothers, professionals and Attention Deficit Disorder (ADD), from a social constructionist perspective, describing the numerous discourses that mothers with children who have been diagnosed with ADD are subject to in Canada and the United Kingdom. Carpenter and Austin (2007) have written of mothers with children with ADHD. These authors do not focus on the condition of ADHD but “the disablement of the mothers of these children.”

While it is possible to focus on practices of disablement, which is done to some extent in the following accounts, I have also focused on what was helpful to the mothers, what strategies and support they found, and how they have developed.

In the following accounts, I have divided the stories in to two sections. The first section focuses on the diagnosis of ADHD, under Point 5.2.3. The second section, under Point 5.3. focuses on the cultural dominant discourses that the women found themselves subjected to and how they negotiated their identity of motherhood within these discourses. These narratives are considered one way of authoring themselves.

5.2.3. The mothers’ accounts of ADHD

5.2.3.1. *How the diagnosis was made*

The reason for describing how the diagnosis was made is to highlight the differences, which are typical of those talked about. Those who argue against ADHD state that there is no robust form of testing, that doctors diagnose quickly and that mothers diagnose their children themselves.

Kevin spent ten hours with a neuro-paediatrician. **Hélène** says, “There were evaluation scales, neurological tests, psychomotor tests, and so on. Her approach included everything. She used psychomotor tests to study how he walked, how he held his body. He had to walk with his eyes blindfolded, and follow instructions to move. All of this material helped the doctor to make her diagnosis in the best possible way” (Lindley S., 2011: 6)

Marie-Jo's daughter was diagnosed at the age of thirteen. She says, "The other one was diagnosed by me. I didn't need to spend a long time to come to that diagnosis. I knew it well enough. One of my daughters said to me, 'and you, have you looked at yourself?' She was right. I was as hyperactive and impulsive as she was" (ibid: 30). She says later, "My son was two years old when I discovered my daughter had ADHD. Straight away I could see that he had it as well. I said to myself, he was made out of the same mould as his mother" (ibid: 31).

Marion resisted the diagnosis of ADHD for her son. She went to the Cantonal University Hospital of Vaud in Lausanne for a diagnosis "because dyspraxia was suspected. We had talked with our family doctor who agreed that we should get a diagnosis. We saw an assistant who observed him [Raoul] for one or two hours. [...] The professor arrived. He saw Raoul for fifteen minutes and I could sense straight away that he was going to impose a diagnosis of ADHD. [...] For me, hyperactivity is when the child moves all the time, who rips apart the waiting room in five minutes. I told him that I didn't agree with the diagnosis. Afterwards we went to see the family doctor, a homeopath, and I got it all off my chest. He said to me, "Well, we will see quickly. We will try Ritaline and if it works, then he most likely has attention deficit" (ibid: 52).

Mélanie explains how she and her husband took Laurent to see the neuro-paediatrician who listened to them recounting Laurent's past, while Laurent took everything off his desk, turned it over and replaced it. She says, "And the doctor thought he was a healthy little boy. But we would have him try Ritaline." The consultation had lasted 30 minutes (ibid: 43).

Kate: *Edward was diagnosed by a privately-practising educational psychologist who had been recommended to me by the paediatrician. Edward had two sessions with her for a 'psychological neuro-pediatric developmental examination'. Her report, dated September 22, 1995, announcing that Edward had attention deficit and various other learning disabilities was about ten pages long. She does not mention hyperactivity.*

Karine does not recount how Alexander came to be diagnosed. She does, however, explain that he does not have hyperactivity, but attention deficit. She says, "it took a long time to discover" (ibid: 24).

5.2.3.2. How did the mother or parents react to the diagnosis

Lupton (1994/2003) describes the functionalist view of illness, as passed down from Talcott Parsons (1951/1987), which posits that once a person has been diagnosed as 'sick', he is freed from most social obligations; not blamed or not supposed to feel guilty for his condition; and needs medical help to be restored to normality (Lupton 1994/2003: 7). The patient is also supposed to be 'compliant and passive' and must want to get better. It seems to me that the relief felt by all of the mothers, expressed to a lesser or higher degree, is that the mothers, too, are freed from blame the moment that their child was diagnosed. I

can remember thinking while I interviewed one of the mothers, “Even if ADHD does not biologically exist, you cannot blame her for wanting it to exist.” I do not want this remark to be taken out of context as a confirmation of my belief that ADHD does not exist. I felt so much compassion for these mothers who had been blamed so often for their child’s behaviour in this society that focuses on the mother-child dynamics to explain children’s difficulties in adapting to societal expectations.

Hélène says, “I was expecting it. It was a sort of culmination of my research. It was almost a relief to know it was that, to have the confirmation, to be able to say that it was for this reason” (ibid: 6).

Marie-Jo says, “It was a relief for me to know, as I was a mother in difficulty” (ibid: 30).

Mélanie says, “I was so relieved. When I came out of the office, he gave me a prescription and at that point in time, the prescription was such a comfort. It was the proof that I hadn’t invented something. At last I could stop being guilty. He helped me stop feeling guilty just with his words. The adjectives he used to describe my son were so positive. [...] Now looking back, it was not the prescription that helped so much, but his listening and the words he used. [...] He could sense our suffering. He saw these totally powerless parents who had tried to find solutions. It was wonderful” (ibid: 43).

Marion, as mentioned above, did not accept the diagnosis at first.

Kate: *I have no recording of my immediate reaction to Edward’s diagnosis. I had been lent a book by the parents of one of Edward’s friends about hyperactivity in the summer of 1995, which I thought described Edward’s difficulty perfectly. So on one hand I felt that it had been confirmed; on the other hand I was not ready to accept the long list of weaknesses she outlined in her report. In my letter dated January 12, 1996, mentioned before, I wrote to the educational psychologist, “I understand little about the complexity of the assessment and the results described in your report, but I am not a psychologist. The important finding for me was that Edward can be helped.”*

5.2.3.3. The choice of treatment

As **Hélène** says, “once we knew [about the diagnosis] we wanted to apply a medical protocol. The research wasn’t far advanced enough to know that there wasn’t one. We were proposed speech therapy, psychomotor therapy, psychotherapy” (ibid: 7). “The doctors are trying out new ideas and their advice is not always correct. Today we can say that there is no protocol. [...] It is not an illness where you can apply a sort of treatment protocol. Each individual case has to be analysed and consider the family environment with all its resources. From what I have learned is that it doesn’t serve any purpose to start a specialized diet if the environment isn’t ready for it. The people will exhaust themselves or feel guilty because they don’t have the appropriate resources. You have to find a pragmatic approach, decide which two or three problems are

major, and identify what can be changed. You have to try to relieve the pressure and help the people to let go, provide a person-centred approach. And, above all, don't give instructions. [...] In the beginning when we find a solution that works for us, we try to impose it on everyone. We're in the phase of telling people what to do. I wanted to obtain results, find the solution " (ibid: 8 and 9).

As already mentioned, the specialized diet is often proposed by alternative medical professionals. In the stories, methylphenidate in the form of Ritalin(e) or Concerta was offered to the children of Mélanie, Marion, Hélène, Marie-Jo, and for Edward. In Switzerland, it belongs in the class of amphetamines that requires a federally approved prescription (with three copies). The mothers' stories reflect the polemic that surrounds the prescription and taking of this medication.

Hélène says, "I was expecting that [the doctor proposed Ritaline] as well, but I had to swallow three times because it is not nothing. It is a dilemma. She gave us fifteen days to think it over. After a lot of discussions we finally decided to try it. [...] But deep down inside, I said to myself that I had to give him medication for his behaviour. I don't often use the word 'drug' because it is not a drug. It is acceptable to give medication for a pain or an illness like diabetes, but for behaviour. We were never happy to do so, still today" (ibid: 6 and 7).

Marion says, "I am not in favour of allopathic medicine. When I had to give him Ritaline, my arm was blocked for three weeks" (ibid: 52).

Kate: I remember receiving this special form of prescription and thinking to myself, "I cannot give my child an amphetamine". But I did. I remember someone telling me that if we thought that Ritaline was not dangerous, we should try taking it ourselves. I couldn't.

On June 25 and 26, 2012 all the Swiss-French newspapers reported about the increase in prescriptions of Ritaline to boys of the age of 12. It is estimated that about ten percent of the population of school children has ADHD.

5.2.3.4. The child's reaction

Hélène says, "Kevin who had trouble stabilising his humour after waking up, found his balance ten minutes after taking the medicine. He could focus on getting going. Later, it was seen to be positive for his concentration at school and for his homework" (ibid: 6). Kevin showed a lot of resistance. He didn't want to hear the explanations. Hélène says, "He told me, "I will eat your pill if you want, but that is it." Every once in a while he would not take it and we would find a packet hidden somewhere. Actually, we knew when he wasn't taking it because there would be remarks about his behaviour in his school report card" (ibid: 7).

Marion reported the most surprising result. She says, "It was dazzling. We tried Ritaline and within a week Raoul had learned to read. Finished, terminated, he knew. He could read because he could at last concentrate." Later, "Raoul was

given Concerta because he had ups-and-downs with Ritaline that were very difficult to handle. I got all the bad moments, when he came down. He couldn't concentrate or control his mood. The Concerta was miraculous. It releases slowly" (ibid: 52 and 53).

Mélanie does not talk of Laurent's reaction. **Marie-Jo's** daughter, Emilie, took Ritaline for a year and a half. Marie-Jo says, "She was sick for a year and a half. She always had stomach and headaches. Now she doesn't want any more medication. She doesn't want the diet either, she wants nothing" (ibid: 31). Her son, Didier wanted to stop the diet when he was six and started infant school. She says, "He wanted chocolate as rewards. And he told me he wanted to eat like everyone, like his friends. I agreed because I thought that three years of diet wasn't bad, but it wasn't sufficient to help him do his homework. I found it good for the hyperactivity, but not for the attention deficit. When he was nine, he would cry over his school work. It was so difficult. So he started medication" (ibid: 33). But it wasn't enough so after two years he was assessed by the school psychologist and was found to have a problem with global comprehension and started speech therapy twice a week.

Kate: *Edward also reported feeling dizzy and having head-aches. I recorded in my personal journal on September 27, 1995, "Says he feels like he's in a dream sometimes, especially when he's at school, like he's not really there." His teacher, Mrs. Iovino, told me, at some point in time, that she didn't mind if he didn't take the "head medicine", as she called it, that she could cope well with him when he started to be distracted. She found that he would happily go to a room by himself and work for a short period of time. When I heard what Marion's doctor had said about Ritaline could confirm the diagnosis of ADHD if it worked, I thought that perhaps Edward did not have ADHD. Who knows?*

5.2.3.5. The circle of people who knew about the child's medication

Hélène explained that Kevin did not want his parents to tell anyone about the medication. The teacher knew because she had been contacted by the neuro-pediatrician during the diagnostic period. She says, "We respected his wish. Later at about twelve, he was more open because he was back in the norm." During the period when they did not tell anyone, a neighbour of Hélène told her how shocked she was by a mother who was giving her three turbulent sons medication to quieten them down. Hélène wanted to tell her about Kevin because she wanted to be open, but she didn't (ibid: 7).

Marion didn't tell the teachers that Raoul had been prescribed Ritaline. As mentioned before, Raoul learned to read in one week. She says, "We didn't tell the two teachers. It was a good test. We sensed that they were angry [afterwards]. Seeing how the [principal] teacher had been treating Raoul I didn't want to tell her. Even with the medication she always found something to reproach Raoul with. Since then I don't do that anymore. I always tell the teachers and the monitors that Raoul has ADHD" (ibid: 52).

Marion says later, “I had a lot of remarks about the medication. People told me it was dangerous, that he would become a drug addict later on. All negative remarks, stupid remarks from our friends. At the end we had to sort out who was a friend and who wasn’t. I couldn’t take this judgement anymore. It was very difficult” (ibid: 53).

5.2.3.6. The doctors who opposed the diagnosis and/or the medication

Marion took her son to see a child psychiatrist, at the bidding of Dr. B. because Raoul had sleeping patterns and she was not sleeping enough and was very tired. Marion says, “The child psychiatrist told her to educate Raoul differently. He told her to let Raoul cry himself to sleep even if he cried for hours. He said I had to be more severe, even if we felt our child was anguished. And then he denied the existence of ADHD, at least he questioned the medication. So again, we were demolished as parents.” Marion’s reaction was to find another child psychiatrist (ibid: 57). Later, she explains that there is a support group for parents in the area but the woman who ran the group told her that she was against Ritaline. She had tried it herself and felt strange.” Marion said she never found the time to join the support group (ibid: 58).

Hélène took her son back to the paediatrician after he had been diagnosed by the neuro-paediatrician. He questioned the diagnosis and the medication. He measured Kevin’s height and weight. He read up about the effects of the medication on growth. He showed them how Kevin’s growth had been slowed down, according to the charts where he plotted Kevin’s growth curve. (ibid: 8).

5.2.3.7. Conclusion

Mothers with children in difficulty look for reasons to explain why their children are different and not accepted by the family members, friends and professionals. These mothers can become immersed in the medical discourses available. Mothers with children who are physically handicapped or have emotional problems suffer more stress than the mothers of ‘normal’ children (Genevie & Marolies, 1987: 268). They have to care for the children who often need more attention, but they also find themselves “embarrassed and stigmatized by their children’s problems (ibid: 269). They talk of being called into school, or called by school teachers, about their children’s behaviours.

Genevie & Marolies write that mothers of children with emotional problems are less likely to feel guilt, “which is not to say that guilt did not exist. On the contrary, one might guess that these children presented such an appalling image, triggered such a deep sense of failure, that mothers could not look at it or tolerate it.” For the authors, these mothers had difficulty in retaining “some closeness and empathy with such a child” and they reported strong feelings of frustration, hostility, hurt, failure, futility and mistrust (ibid: 272-274) in their relations with their children.

While the battles continue with raging medical professors and desperate mothers, it seems appropriate to ask, “why do we spend our time on assigning responsibility and blame when the children and the parents are experiencing problems?” If all the investment of time and effort in research and medication could be directed towards finding solutions, and we focused on collaborating together we might be able to alleviate some of the suffering.

We cannot expect that mothers define ‘motherhood’ and exclude all others from telling us what it should be like from their point of view. However, as mothers, we can tell you about what was or is helpful to us.

5.3. Discourses about motherhood in mothers’ stories

In this section I recount the mothers’ stories about their experiences. I have highlighted the mothers’ names so that you can follow each one’s specific story. I have included my voice in italics.

5.3.1. Children on the move with mothers who enjoy them

Hélène: “When he was little, we didn’t know [about ADHD]. We said, “how lively he is!” It wasn’t a problem for us at all, absolutely not. We wanted a child like that. We dreamed of having a boy exactly like him. We called him Kevin after the boy in the film, ‘Home Alone’. [...] When we saw that film, we said to ourselves that we would call our son Kevin like this mischievous and high-spirited boy. He became like that. He is very resourceful, and he has a survival instinct. At the age of six, he took the bus to go on his own to his music course. He always knew who to address, whom to call, if need be. He was able to manage on his own” (Lindley S.: 1).

Mélanie: “This child was very much desired. I had a lot of trouble to have him so he was very much awaited with so much happiness and impatience. He could only be magnificent, handsome, intelligent, sociable, and open to everything. He was lively, open, and he did so many things. At the age of one and a half, he jumped off the diving board and climbed up everywhere. I found it so magnificent” (ibid: 37).

Karine speaks of how much her son was liked and appreciated for his love of life, his physical well-being and his kindness. “In the crèche where he was one of the pillars because he was there full-time, he was such a happy, laughing child.” (ibid: 17) She also says how having children brought back happy memories, and allowed to re-discover some of the joys of childhood. “With my children, I started making sand castles. I found that childish creativity again, that moment of joy with your feet in the mud and sand everywhere. We made castles that we thought were so wonderful, and all that joy of living made me hungry for life again. I found so much optimism again being a mother” (ibid: 23).

Kate: *When Edward was 14 months, in February 1986, we moved from Rabat, Morocco, to Lens, a mountain village in Valais, Switzerland. His father had purchased a little blue and red car for his Christmas present. He rode it when we went out for “our daily trot” (Letter to my mother dated May 5, 1986) every day, staying out for at least two hours. He was cheerful and energetic. We would stop at the school playground and he would go up and down the slide. From the playground back down to the village, there was quite a steep hill. He would go down using his feet to brake. He was constantly on the go, and I was always running after him. My sister-in-law wrote to me (July 2, 1986) “We hear he’s quite a chirpy little chap who’s into everything.” I wrote to my mother on September 9, 1986: “Yesterday he was really super and we went to a playground with Elisabeth and her son, Nicholas, and he didn’t stop for two hours. He climbed up the highest slide, played in the sandbox, stole some kids’ toys, and ate all Nicholas’s biscuits, and so on. But he was happy.”*

These mothers are saying that they enjoyed their children. They had wanted to have children. Both Mélanie and I had medical treatment to help us have a child. This is one story, or one discourse, the discourse of enjoying our children, of being rewarded by having a child who was lively, energetic, and boisterous. When does our enjoyment of lively, energetic and boisterous children diminish or stop? Is it when they are described as being out-of-control, over-bearing, and naughty?

5.3.2. The first chords of discord

Marion: “When Raoul was small, he was always on the go, always moving. When he played he made noises like guns firing, and so on. Many people told us he was hyperactive, but for me that was not hyperactivity. He played quietly for hours with his Playmobile toys; we wouldn’t notice him. You have to know that he is adopted, that changes the story a lot. During the first two or three years, he physically clung to me. I had to cook holding him. He needed to be reassured” (ibid: 49). Marion took her son to see a child psychiatrist because she felt he was not yet ready for school, at the age of three and a half, and he had trouble sleeping. She said, “What he said hurt me the most. After six months of therapy, the psychiatrist told me I was imagining things, that Raoul was doing very well. He said that I needed to hold him. He actually told me that when he read him the story of *Dumbo* – with the mother chained up, how significant! (she laughs) – he [Raoul] remained quiet” (ibid: 50). *Dumbo* is a children’s story written by Helen Aberson, which was made into a film by Disney. Mrs. Jumbo, a circus elephant, has a baby. “The baby elephant is quickly taunted by the other elephants because of his large ears, and they nickname him ‘Dumbo’. Once the circus is set up, Mrs. Jumbo loses her temper

at a group of boys for making fun of her son, and she is locked up and deemed mad."⁶

When **Mélanie**'s son, Laurent, was two and a half years old, she put him in a private preschool. It was then that she discovered that he was particular, outside of the norm, as she calls it. "The supervisor thought he was magnificent because he was already toilet-trained at the age of two and a half. It was wonderful for her. But, unfortunately, he did not fit into the social frame of reference. The other very important thing for her was that he should know how to put the toys away. He did not put his toys away. So when I picked him up at four o'clock, she would complain to me. "You see your son did not put his toys away. He took all of them out, and he doesn't want to put them away. He took all the straw out of the guinea pigs cage and it took me twenty minutes to clean up. I don't know what to do with him"(ibid: 38).

For **Hélène** it was when her son, Kevin, was hospitalised at the age of sixteen months to have drains inserted in his ears because of recurrent ear infections. "In the hospital the nurse wanted to record his blood pressure and he would not let her put the sleeve on his arm. She got angry with him and told him that he would break her machine; that she would not be able to record his blood pressure. She put the fault on me. On top of it, before the operation, he wasn't allowed to drink. When he woke up after the operation, he was very thirsty. He was given a glass baby bottle. He treated it like he treated his baby bottle at home; he drank and threw the bottle on the floor. It broke and there was a monstrous outcry in the hospital" (ibid: 2). There was also the homeopathic specialist who she consulted for Kevin's ear infections. "He was slightly laid-back. He put candles on the floor and walked barefoot. He had lots of Asian art objects. Every appointment was a nightmare. My son would take his office apart. The only thing he liked, and would remain still for, were the small, white globules that were put under his tongue. I was grateful because from then on Kevin didn't need to take antibiotics any longer. The doctor was competent for that and I had made the right choice to take my son. But towards the end of the treatment when Kevin was twenty-four months old, the doctor told me to spank his bottom if I didn't want to have problems with him later on. I can't remember exactly what his words were, but he said that from time to time it would do [Kevin] a great deal of good" (ibid: 3).

Karine remembers that the first person to make a "destabilizing and destructive remark" about her son, Alexander, was his teacher in first grade in infant school. Alexander would have been about five. Until then he had attended a crèche. "The first person, who I remember, was the infant school teacher who must have been at least twenty years old. She asked to meet me in April because

⁶ Retrieved from <http://en.wikipedia.org/wiki/Dumbo> on August 20, 2012

my son ‘had problems’. When I asked her the nature of the problems, she said that he was not able to write his name, and the other children could, and it was, of course, extremely serious. She said to me, “... you understand,” and I was so shocked because I thought that it was only the older generation who said such things, “you see, because you are a mother who works full time it is normal that he is lagging behind because you don’t have time to look after him” (ibid: 20).

Kate: *In September 1991, at the beginning of the school year, I was approached by Edward’s teacher who was also the Head Teacher for the primary school. Edward had just started first grade and was approaching his seventh birthday. She said to me, in the car park at the end of the school day, that she was at a loss with Edward. She used the word, “désemparé” which can also imply being “distraught”. She didn’t know what to do with him. (Letter dated January 27, 1992).*

Mélanie also received similar messages from her son’s teacher in infant school. She showed a film of the children having a party to Mélanie and her husband. They could see Laurent sitting on his own, isolated from the other children. The teacher made negative remarks constantly about him. Mélanie says, “they all meant, ‘do something because I cannot stand your child’” (ibid: 40).

5.3.3. The experienced effects of negative messages on the mothers

I have chosen these few examples because they were all made when the children were relatively young, or the mothers interviewed remembered them as earlier remarks which impacted them. These excerpts are taken from the answers to the question, **“What remarks did you hear that were not helpful? And how did you react to them?”**

The effects on the mothers can be described in terms of emotions or psychological distress. The various reactions include being hurt, crying, being ashamed, angry, resisting, feeling self-doubt, frustration, and rage. These terms can easily be categorised as ‘intra-psychic problems’ that “locates problems within the internal psychology of the individual” (Burr, 2003: 122) rather than as problems created by being positioned in a particular way by others. The mothers in my inquiry seem to have found themselves placed in positions that they did not find helpful, and which they could not easily negotiate.

Marion talks of how hurt she was. Later on when a school assistant told her that her son shouldn’t be enrolled for school because he wasn’t ready, she said she almost burst into tears. Sometime later she told the assistant’s manager and cried in front of her (Lindley S., 2011: 50). Early in the interview, she says, “I am still upset and sad too. One develops an extreme sensitivity. It’s terrible how everything affects you because you have such difficulty in ensuring that your child advances, develops, evolves and grows up” (ibid: 49).

Mélanie explains how she got down on her knees and cleared up the toys that her son refused to put away. The remarks made by the supervisor “would have been banal had it been not for the fact that she said them in front of the other mothers.” While she was on her knees, she tried “to close myself off so that I couldn’t hear the laughing and smiling. It is terrible to say that you can hear people smiling behind your back.” Mélanie withdrew Laurent from the preschool because it was too difficult for her to deal with the complaints and manage her emotions, because she got so angry (ibid: 38).

Hélène explains how remarks were often made to her child, not directly to her, but that she took them for herself. She didn’t know quite what to do. It seemed to her that her child did not correspond to the expectations of the hospital as to how a child should behave, nor did she correspond to how a mother should behave. She said what struck her was that in a children’s hospital they wanted an object, not a living child. (ibid: 2) With the homeopathic doctor, she was angry that he should propose hitting a child and that he should question her parental authority. She said, “at that moment, I hadn’t started to doubt, I resisted. But after so many remarks that kept on coming, we started to doubt our way of doing things, our way of educating” (ibid: 3).

Karine says, after having heard the primary school teacher talk of her son, “And then and there, I asked myself if I would kill her, and then cut her up into small pieces. And then, of course, after the anger comes the overwhelming guilt. We are constantly made to feel guilty by our circle of friends and family” (ibid: 20). In a further example, she describes the occupational therapist who tells her that Alexander will never be able to write properly because he has such “fat fingers” as not only incompetent, but spiteful. She says, “That hurt because we do not like people who are different, and we suffer from being different. Personally I was quite large for various health reasons, so I was called the ‘fat Arab’. It is an emotional subject. And when I heard that my son’s fingers were too fat for him to write properly, I found it a physical condemnation and I have a lot of difficulty with that. It is as if you would reject any child with any handicap” (ibid: 22).

Kate: *When I think back to what the teacher said about me, I find myself invited into a position of defence. I say that I remember thinking certain things, but those thoughts have become practised over the years. For me, I remember thinking three things about what the teacher said to me about Edward. The first, I thought that a teacher should know how to deal with the children they teach. They should have teaching methods that they have learned during their studies and internships, e.g. “if the child is bored, then do this ...” The second is that if the teacher has difficulty in her relationship or in her interactions with a child, which would cause her distress, then there should be supervision for the teacher. I remember later on, telling another parent of another ‘naughty boy’ that perhaps it should be the (same) teacher who should be going to see the psychiatrist and not their child. In my studies in Educational Sciences (Faculty*

of Psychology and Educational Sciences, Geneva University), there was a class with Mireille Cifali where students were expected to take a difficult situation related to their teaching practice and reflect upon it. It was, admittedly, a psychoanalytic course, but there was someone who was saying something along the lines, "if you have a problem with a child, it is not necessarily the child's fault." The third point was more of a visceral reaction, a resistance to being held responsible for explaining my child's behaviour in the classroom. At that time, I had done four courses related to Adult Education in Educational Sciences and I had no practical experience of teaching children. I did not know why my child behaved the way he behaved in the classroom, and I thought that she, as a professional, should know if not why then, at least, how to deal with it. From my point of view, she was incompetent. Mothers of children in difficulty are often asked to help professionals and/or adults to deal with their strong emotions related to their difficulties interacting with the children. I not only could not explain my son's behaviour but I couldn't act as a therapist for this teacher.

5.3.5. Reflection

From the above stories, we can glean some of the expectations that various people had of these mothers. The messages given are understood by the mothers as not fulfilling the expectations which, in turn, seem to invite them into a variety of positions, some of which blame the professionals, or justify their own way of doing things. The performance becomes one of conflict. Here are some of the ways that those messages can be reworded to highlight the underlying values and beliefs of the professionals involved. These are my interpretations.

- Marion should hold her child all day and read stories to him. A mother should put her child's well-being above all other tasks. She has nothing else to do in the day. Mothers who do not dedicate all their time to doing what is considered appropriate for the child are ...
- Mélanie should clean up after her child at pre-school because the teacher cannot encourage or incite the child to do so. Mothers who do not clean up after their children are ...
- Hélène should make her child comply with the doctor's orders. She should make her child sit down and not touch the artifacts or the burning candles that the doctor has littered all over his office. She should use physical force or spanking if necessary. Mothers who cannot control their children are ...
- Karine has a son who cannot write because she does not take care of him because she works full-time. Mothers should not work full-time. Children whose mothers work full-time are not taken care of. Children need to do their homework with their mother. Mothers who don't do homework with their children are ...
- Kate has a son who does not behave as the teacher would like to, although Kate is not sure of the teacher's exact expectations. Mothers

who cannot explain why their children are one way or another, when the children are out of their sight, are ... Mothers who do not want to console teachers for having to deal with their difficult children are ...

5.3.4. The discourse of blame

In the interviews the mothers used the word “judge” quite often, indicating the performative sense of judgement as in “being criticised or blamed”. **Hélène** talks of being constantly judged by family, friends and teachers, and then she gives some examples where the opinions were told to her. “A friend told me something about the fact that I worked. She said to me, ‘Oh well that’s alright for you. You can realize your potential, and it doesn’t matter if the children suffer.’ I was gob-smacked. Somehow she was telling me that she admired me, but on the other hand, she said that the children would be ‘paying the bill’ in the same sentence! I should have said to her, ‘Can you hear what you are saying?’ It was a form of lack of awareness. [...] I’ve understood that I shouldn’t listen to that kind of remarks. You should listen to them with the ears of the giraffe, as Marshall Rosenberg, says. You shouldn’t internalize them” (ibid: 4). **Hélène** goes on to explain that mothers who don’t work are also criticized. “If a mother doesn’t work, she will be labelled hysterical or depressive. Mothers who want to continue their careers are egoists. There has to be a weakness somewhere because they cannot succeed in both the career and the family. It is not possible. So therefore they will look at the moments when the child does not behave normally, and because all children at some point in time do not behave normally, they will always find something. And it is always the fault of the mother at all levels. If the child does not behave as he is supposed to, it is the mother who cannot handle him” (ibid:4).

Being situated in a discourse, we find ourselves not only products of discourse, but also consumers and producers of discourses (Bava, 2005). Some of the mothers explain that they can also judge or blame other mothers. **Mélanie** says, “It is difficult. I find myself sometimes judging others gratuitously, but it is human” (ibid: 47). **Hélène** says, “I think that I judge as well. I don’t deny that I have said or done things that have perhaps offended others, simply because I might not have thought about it. Stereotypes continue to be enforced with this kind of messages” (ibid: 4 and 5).

Greer (1984: 2) talks of the ways in which we, in the Western world, show that “we do not like children.” She writes, “If ours was a society which welcomed and enjoyed children, and if each parturient woman was surrounded by people who wanted her child even more than she did, she could ease her feelings of responsibility and inadequacy. If ours was a society with collective notions of normative behaviour for parents, parents could escape the crushing responsibility for the ills that befall their children, they would be aware that they had fulfilled all expectations. Where there are no shared expectations there can be no feeling of having done the right thing” (ibid: 9).

5.3.6. Strategies that mothers found dealing with professionals

It seems to me from the stories that are told that many of the mothers started to develop strategies to deal with professionals who were positioning them as failures, by blaming them. To listen to the stories, is to have the impression that the mothers were being ‘assaulted’ by them. It seemed, therefore, that it was very often from a defensive position that they developed strategies with a two-fold purpose. On one hand they were trying to find ways to help their children or alleviate their children’s difficulty and secondly, to protect themselves from further unexpected assault. It was as if they came to expect the assaults and took initiatives to prevent them, to the extent that one could imagine that the professionals came to perceive the mothers’ initiatives as assaults.

Karine, in particular, tells of various ways that she put into practice. In relation to the incident with the infant school teacher who had said that it was normal that Alexander couldn’t write his name because he had a mother who worked full-time and who couldn’t, therefore, take care of him. “I asked for another meeting, and then I told her that I demanded a written summary of her observations in class that would justify consulting a specialist. I said that if there was a problem I would not wait for it to grow. [...] Now I go to see the teacher at the beginning of the school year. The teachers tell me that I should leave them some time to observe, and I agree. I want to make things clear. I tell them that if they observe anything special, they should tell me quickly. We don’t wait for the end of the year or the end of the semester. They have to say yes to me because I insist. I camp outside their office until I have a meeting.” (Lindley S.: 21)

Karine explains further, when asked about how she developed through her relationships with others as a mother, “I knew how to defend myself, but now I defend myself more effectively. I am a lot less taken by my emotions. When I am faced with an attack, or what I consider to be an attack, first of all I clarify what the person wanted to say, what I understood. I also learned how to do that. I say, ‘When you say that, does that mean ...?’ I try to be precise, as in the case of the fat fingers. I asked, ‘is it a problem because you think his fingers are too big? If not, explain yourself. I expect an explanation.’ I understood that. It helps me to clarify certain things. I put my emotion to the side and I go at what is essential. ‘So now that you have told me that, what do you expect? Where is the action plan?’ And at certain points in time, I say ‘no’. If I judge that something is not right, for example when I was told that I had to take him to see a speech therapist because he had a slight dysorthographia, I said, ‘now that is enough. He does sport. He goes to school. He passes [his tests] even if just by the skin of his teeth, but now I think that we will stop here and now. We will not go to the speech therapist.’ There comes a moment when it is all too much.” (ibid: 24)

Mélanie tells stories of how other mothers’ remarks were hurtful to her. In her stories, she tells of the shame of being remonstrated by the supervisor at the pre-

school in front of other mothers, having remarks made by another mother about her child while waiting in the doctor's waiting room, and other mothers who criticise her child in the playgrounds. She explains that she started a parent training class based on the Howard Glasser method, and learned to make clear requests. She says, "There were always ups and downs. But it helped me to preserve a sense of myself when others would make remarks in the park or in the St.. I didn't keep quiet anymore. I no longer hid myself. I wasn't ashamed anymore. I would simply say to the mother who made the negative remarks, 'I think you must be the ideal person to bring my son up. So I will give him to you for two or three weeks and like that you will transform him for me, and I will be the happiest of mothers. I shall go and prepare his suitcase.' I answered back; I didn't let them walk over me anymore. If these people have such an ability to know better than others, then it is true that they should help those who are in trouble. (She laughs) I said it very sarcastically and then the people would shut up because they didn't expect me to say that. I'm sure no mother had ever offered their child to them to educate. I think I started to say what I had been feeling for all these years" (ibid: 46).

Kate: *I received a letter from Mrs. T., the private educational psychologist, dated 11 January 1996, in which she wrote, "Edward is a child in great need. I do hope that you have followed up on all of my recommendations; medication, extra language therapy, psychological counseling for Edward and management techniques for parents and school. Based on extensive research, this multi-modal approach is highly recommended by Harvard Medical School and other outstanding medical centres in the USA. A child with language development problems, attention deficit disorder and a very damaged self-esteem (stemming primarily from his language and attention weaknesses) needs help on all fronts. If he does not receive it, his future can be very compromised indeed. You are among the very few parents who have not kept in touch with me after an assessment. I am concerned for Edward and would be very interested to know the support he is receiving."*

I wrote back to her in a letter dated 12 January 1996: "You say, "I am concerned for Edward and would be very interested to know the support he is receiving". Let me say this: Edward spends 260 days of the year with me. I am the person who is in charge. I made a career and life choice three years ago to work as a freelance training consultant, and to earn less than before, so that I could devote more time to my children's upbringing. I am in the final stage of three years of psychoanalysis. I have trained as a co-counselling therapist. I am a responsible, courageous and positive mother. As you know what it is like to live with a child with weaknesses such as Edward's, then you realize just how important those characteristics are. I have learned that at the end of the day I am the person who bears the responsibility of what happens to my children totally on my own. I have learned that people who carry titles such as psychologist, doctor, speech therapist and teacher may have opinions, but that they don't reduce the weight of responsibility upon my shoulders. I pay to hear

those opinions – and I choose to do what I want with them. I'd like to remind you that I was the one who kept on researching Edward's case and searching for alternatives. [...] I now tell such people that if they want to give their opinion on what he needs most, then they have to spend at least two hours a week regularly with him.

What is missing from the above account is the first page where I enumerated all the things that I was doing for Edward, the progress he was making and the feedback from his teacher. I did, in some way, hold myself accountable to her and it seems clear that I was angry for being asked to account. However, the idea of telling people who wanted to give me their opinion that they had to spend at least two hours a week regularly with him was a practice that I kept to. My sister-in-law, Annie-Laure, took me up on it, and had my two children to stay with her during the summer holidays. She later told me that her own sister had never let her take care of her niece and nephew and she was thrilled that I entrusted my children to her.

5.3.7. Investment of time and other resources

In addition to talking back or talking up, the mothers also talk of the additional hours they put into doing homework with their children or taking them to appointments. **Marie-Jo** explains how their lives are run by Didier's lessons and his bi-weekly sessions with the speech therapist. She explains, "I prepare his lessons, but I don't do them and I don't help him do them. [...] I prepare, for example, all the vocabulary in German and French on post-cards that are stuck on his wall. Everything that he has to learn is transformed by NLP (Neuro-Linguistic Programming). His speech therapist showed me how to do it. And then there is a website called 'BICEPS' which has been made by some people in Fribourg and he does his lessons on that. Everyone who has children who have school problems uses this website. It is fantastic. It was created by the Toscanelli family. [...] In BICEPS there is the Swiss-French syllabus and you can make up your individual lessons. I put in my son's entire French vocabulary." Marie-Jo found out about these ways of helping herself through her own research. She says, "If I had listened to the school we would have stopped looking and he would have school difficulties and he would have finished up in remedial class" (Lindley S.: 34).

Marie-Jo also introduced a specialized, but restrictive diet at home. She says, "We went to see E.A. in Geneva for help with the diet. For three years we had a diet free of gluten, phosphates and casein. Yes, (she laughs) I have a lot of determination. Didier had that diet from the age of three to six" (ibid: 32).

Kate: *When Edward was a weekly boarder at the Maya-Joie boarding school in the Valais, he took a big bag of food with him every Sunday evening. To fill that bag with milk alternatives, gluten-free cereal, and snacks, I would go to five different shops in the Geneva area each week. There was a bakery in France that made gluten-free, dairy-free cakes. There was another shop that sold fruit*

syrups with no additives. There was the butcher in Grand Lancy who sold ham without phosphates. There was a shop in the centre of town that sold dairy-free chocolate. I threw out all the food with additives and banned cola based drinks from home.

Marion talks about helping her son to do his school work. She says, “In the first and second grade, it was really difficult. We worked so much” (ibid: 53). She decided to change professions and undertook three years of training as a day care centre worker (ibid: 55).

Hélène and her husband decided to put Kevin in a private school in Lausanne when he was in fourth grade. They also put their second son in the same school. This implied driving the children to school some days, as well as the financial investment, but as Hélène says, “We were comforted in our choice. That school was like his home. Everyone knew him. He was accepted in the school. There were 350 students, and everyone knew each other. The receptionist allowed him to leave his scooter at the receptionist. There was a family atmosphere. He continued to have his small difficulties to concentrate, but he didn’t perturb the class” (ibid: 11).

5.3.8. Supportive and helpful messages

The helpful remarks that mothers received were as **Karine** says, “from the same group of people, especially the professionals in the teaching world and a couple of doctors that made certain remarks.” A teacher who was also a mother, whose own child was diagnosed with a very high IQ, told her that she shouldn’t worry about her son, “Your child will do well in life, even if at school it is difficult. He is a deeply intelligent, imaginative and creative child who doesn’t, like other children, fit into the school system” (ibid: 20).

The teacher who looked after Alexander’s special educational needs and who taught him how to structure his homework, also told Karine that her son was very willing and wanted to cooperate. She said that it helped her to calm down, to know that he was doing his best, and it defused her anger when she thought he hadn’t tried to learn his vocabulary (ibid:16).

Marion also explains that finally in third grade, “Raoul had three wonderful teachers and I started to hear that I had a wonderful little fellow. They gave me so much encouragement about him and his behaviour. I even had a ‘thank you’ in his report card. I had never heard that in my life.” When he was in fourth grade, Marion wanted him to repeat the grade because of his weaknesses. This is a common practice in the Swiss-French area. Roughly ten per cent of all primary school children fail to “graduate” at the end of the school year and have to repeat the year. However, Raoul’s fourth grade said that it wasn’t fair considering all the work he had put in. Marion says, “I had such wonderful feedback about our family, just positive remarks. I wanted to thank her because there are such few people like her. It gave our family confidence” (ibid: 54).

Hélène talks about the day care centre worker who told her that she could rely on her, that she was doing her job by taking care of her son, and that she went off-duty in the evenings, whereas Hélène could not. (ibid: 10) This remark relieved her because she had started to think that no-one liked her child or could put up with him after her interactions with the medical professionals. She also talks of Dr. Junier, a well-known, retired paediatrician in Lausanne, “He is the grand-father of all the mentally and physically handicapped children. He is the defender of the mothers and fathers, more often the mothers because he sees them more often. [...] He gives conferences on learning difficulties and the other ‘invisible handicaps’ as he calls them. He defends the families when it comes to education. He says it is not a question of education. These parents are doing all they can, more than other parents, and they still get remarks such as ‘could do better, does not behave the way they should’” (ibid: 9).

Kate: *The family therapist, Dr. A., whom I started to consult in 1992 following my separation from my husband, told me at one point in time that I was a competent mother. It must have been in response to me berating my ability as a mother. He said that my way of being a mother was appropriate for Beatrix, that she was doing very well in school and in life. At the end of our first session, he told me to come back alone for the next session and he would teach me ‘leadership’. He taught me many practical ways of dealing with specific difficulties that I encountered with the children, in the few sessions I had over the next three years. He showed me how to take charge of a situation and offer possibilities to the children that were in line with what I wanted to offer.*

Hélène talks about a teacher who helped her to deal with her son’s difficulty to get to school on time in the morning. It seems that the teacher’s attention towards Hélène was noticed by her son, and he thought about the problem and proposed a solution to his mother when she picked him up from school (ibid: 12).

5.3.9. Family support

Hélène talks of her mother in the early days when she found it difficult to handle Kevin in public. She says, “She comforted me. She told me it was not the end of the world, and if I was not on my son’s side who could he count on? She told me to take up my role and my place, to find my resources as an adult to find a solution. I knew I could always count on her” (ibid: 5). Of her sister, she says, “she is an extremely important resource for our family, also for Kevin. She has no children of her own. She has always been by our sides. When it is difficult, she will take him. He can go to her and complain about us to her. [...] It’s clear that in some families these resources are cruelly missed. If the grand-parents aren’t understanding, or the neighbours, or the circle of friends, it impacts the evolution negatively” (ibid: 13).

Marion talks of her parents, “who knew how to support us. My father gave me so much recognition as a mother, a good mother. He told me such wonderful

things about the way I was with my children. My father would come to take over early in the morning so that I could go to work. My mother helped me by taking the children one day a week so that I could get away and recharge my batteries in the mountains. [...] As Raoul slept very badly, my mother would take him to sleep at their home once a week so that we could sleep. It was a present. Thank goodness I had them. They were so incredibly proud that we had adopted the children” (ibid: 54).

Karine talks of her sister who understands Alexander’s ‘special way of thinking’. She says, “I have to say that he is very similar to my younger sister. She is exceptionally gifted and succeeded at school. [...] She and my son understand each other’s way of thinking very well.” (ibid: 18) Karine goes on to explain a recent example of how she explained to Alexander how her husband had to take his favourite hunting dog to be put down. “And then he said, ‘So he is not well.’ and I said, ‘Of course the dog is not well.’ And Alexander said, ‘No, I meant, Papa is not well.’ When I told my sister this story, she understood straight away that Alexander was referring to my husband” (ibid: 18).

Karine tells me later that she grew up in a family of independent women and “unfortunately I learned to cope on my own. [...] That way you don’t owe anyone anything. You do it yourself. It is you who is responsible. You do your business. You have to manage. It’s your job! I learned that. We didn’t learn to ask for support in our family. We go and ask professionals for help and they are paid for their help. We keep ‘the stiff upper-lip’. We have to show that we are strong, don’t we? It is one of the limiting messages from my childhood: ‘Be strong’. I thank Papa for wanting a son and having me (she laughs).” (ibid: 26) Her father was Afghani, and she says that there is a notion of debt in the Afghani culture. If you ask for a favour, you have a debt towards the person. You are considered a weight if you ask a person for help, so you only ask for help if you really have to. She says, “You don’t realize how strongly you have been influenced” (ibid: 26).

5.3.10. Support from the association for parents of children with ADHD

Hélène talks about how she contacted an association for parents of children with ADHD in Zurich, in the Swiss-German part of Switzerland. They told her about the Swiss-French association that was having an information day for parents early 1998. Hélène says that she received a lot of information and attended conferences. She built up her repertoire of knowledge which she uses, with her own experience, to guide and support parents today as the president of the association ASPEDAH (ibid: 7 and 8) It was also an opportunity for her to step up. She says, “I understood that I became more vociferous within the association, perhaps because I took my role to heart. I remember that I was not like that to start with. Now I can stand up to the most qualified of all professors. I don’t encroach on his domain of expertise. I respect his competencies. But, on

the other hand I defend the domain of the parents. We have our parental competencies, and no one should come and tell us what to do, especially not the doctors. We can cooperate in partnership. It is not a hierarchy” (ibid: 13 and 14).

Marion talks about how the association ASPEDAH became her life-saver, “There is no other term for it. The secretary, a Swiss-German woman, listened to me. Thank goodness she was there. Until then I was floundering. I cried a lot. I was all alone. From then on, my life changed. It became clearer with the association. It was impressive. (She rubs her forearms). I have goose-bumps. What changed was that I became confident that we were going to be able to do something for Raoul” (ibid: 53).

For **Mélanie** and her husband who found out about the association after their son had been diagnosed with ADHD, it was a blessing in disguise to join the support group. She says, “Indeed we found that we had our own normality with children whom others call ‘outside the norm’ within the group of parents. Within the space of one evening, we found our normality. (She laughs). It does you so much good to feel normal for an evening. We developed perhaps a sense of normality that is abnormal, but which remains normal for us. I don’t know if you get what I mean? (She laughs) It is perhaps mean of us to think that the others are actually abnormal” (ibid: 43 and 44).

In a discussion with Dr. B., a paediatrician, on March 7 2011, he said to me that many parents in the Swiss-French area keep their children’s diagnosis secret, and to attend the meetings of an association would be to publicize that their children have been diagnosed. However, he said that there was an important role that a large association is the one of political lobbying. If all the parents whose children were diagnosed with ADHD were part of the association, they could start to ask for educational reforms.

The main reasons for joining the association ASPEDAH given by Marie-Jo, Mélanie, Marion and Hélène, were to gather information, be able to exchange experiences, to find someone who could listen and knew about ADHD. Each of them is now active within the association; they have found a sense of belonging. They are also able to “give back” in return for having received support. During the years of bringing up their children, none of them worked full-time in paid employment.

Karine is not a member of this association, but she is part of a fishing school and teaches children how to fish ethically. She says, “I have a bit of difficulty with associations in general, but it is a personal point of view. I am quite happy to share my experience. In associations I have a lot of difficulty situating myself because I am not very typical. I had a non-practising Muslim father, a non-practising Protestant mother and a very Catholic nanny. I lived in an international environment, a boarding school. So I am careful with associations.

I cannot adhere completely to the rules, or if I do then there are very few constraints in the particular association. I join my son, in the same sense, that I have a visceral reaction towards authority and refuse it, even if I have a lot of respect for the hierarchy who dictate the standards. I have more and more difficulty in accepting that people want to dictate how I should do things. The older I get, the more difficult it is. It will be terrible when I end up a hermit on the top of a mountain” (ibid: 25).

Karine’s experience resonates with me. I, too, am not a typical Swiss. I moved to the Swiss-French area when I was a young adult from Zurich where I had learned to speak Swiss-German fluently. I was able to go undetected as a foreigner. However, I speak French with an English accent, and find that people often remind me that I am a foreigner. Also, like Karine, I also worked full-time in paid employment and found myself part of a minority group in the rural village where we lived. Full-time stay-at-home mothers were the norm. I belonged to the association, separate from the officially recognised parent-teacher association, which provided supervised lunches on the school premises. Our children were sometimes pitied by teachers and stay-at-home mothers who felt that it was unfair that our children couldn’t go home over the lunch break. I went once to an association in Geneva for parents of hyperactive children.

Kate: *I remember going to my first meeting at the Hypsos association in Geneva in 1999. The woman running the association, E.A. told me to come along and meet other mothers. I remember introducing myself to a group of mothers. They seemed to be good friends, full-time stay-at-home mothers, and I felt I was interrupting their conversation. They weren’t particularly friendly and nobody gave me any practical advice. E.A. had a bound collection of articles, information on food and diet. I bought that and fled.*

5.3.11. How the mothers have developed through their relationships

Karine says, “Being a mother has allowed me to become more solid in regards to other adults, and in the world of adults, to position myself as one adult towards another adult. I am no longer the young girl or woman facing the one who knows or has the experience” (ibid: 23). She also says, “You get to know yourself better. It is very revealing, and sometimes destabilising. You notice your weaknesses. It takes you back to your own childhood and the things you missed out on. It allows you to sort out certain things about your own parents. It’s interesting. It’s very liberating” (ibid: 22).

Mélanie says something similar, “It was [Laurent] who helped me to become a responsible woman, not a mother. This life experience made the person who I am today, someone who listens and who tries to never judge anyone else. [...] It was him who made me grow up, who healed me of all the family pains and constraints. He taught me to let that go, to understand how my family

functioned, and to detach myself. To become a fully-fledged adult, to take my rightful place” (ibid: 47).

Marion thanks her son for her personal development. She says, “Now I realise that I am a more competent childcare worker above all because of what Raoul has given me. He obliged me to work on myself, to move on. And now, I feel that I can give some assistance to the other mothers in difficulty. It is thanks to Raoul, without him I would never have made this progress. He is tiring but he is fascinating” (ibid: 55).

Among all the skills that **Karine** enumerated was the ability to multitask. She says, “I never thought I would be able to do so many things. With hindsight I realize how many managerial abilities we have. Now that I work in the corporate field of training, I see all the courses on management, time management, leadership, coaching. We do all of that. We develop all those competencies: active listening, coaching, and so on” (ibid: 23). She also explains that she has become a competent paediatrician, she can diagnose many illnesses and knows how to treat children, dogs and cats, and even her husband. She became a better cook. She can make a good meal for seven people quickly (ibid: 24).

I have recorded earlier how **Hélène** in her role of president of the association became more vociferous, and how she can stand up to the professors and can cooperate in partnership. She says, “it is on this playing field that I have my revenge today. I didn’t do it for him [Kevin] or for myself because, so often, I found myself speechless, gob-smacked. [...] Today I can be the spokesperson or the advocate of the other parents who haven’t had time to stand back. I have perhaps become the advocate that I wished I had had” (ibid: 14). I would like to applaud Hélène, and have done so after her welcome speech at the symposium in front of four hundred people, but also for the way she followed up on the symposium with the organizing professor. She insisted on having a feedback session although it took about a year of insisting.

Marie-Jo told me straight away in our interview that she was a mother first of all, whether or not her children had ADHD. She also told me that she had never heard any negative or hurtful remarks. She says, “We never had big problems. At home it was difficult for me, but when the children were away on vacation with other people they never had any problems.” I would suggest that Marie-Jo sees the difficulties as individual and personal. She told me how she consulted a doctor when the girls were small, and he told her, “You are going to take some time to look after yourself and you will see that you will get better. Do something, do things that you enjoy doing while the girls are at school. “ Marie-Jo says, “I will thank him for the rest of my life. It was the biggest insight of my life”(ibid: 29 and 30). Elsewhere she talks of her “strong character” (ibid: 32). She told me how she had to write a letter of apology to a teacher after telling him and the school psychologist that they didn’t know all there was to know

about ADHD, and that her son might be atypical but he did have ADHD. She says, “He said, “if you don’t write a letter of apology, I will file a complaint against you.” And I thought, “just you wait, my friend, I will write what you want, but I will continue to think what I think.” The liberty to think is the best thing in life. So I wrote his little letter saying that we had had a misunderstanding, and please excuse me, etc. He had his letter, but for me he is still an idiot” (ibid: 35).

Marion, like **Hélène**, talks of “growing a thicker skin, an outer shell” (ibid: 53) and I told her that I thought that she had developed more confidence (ibid: 55). She says, “There are times when I complain because there are little idiots who can still hurt me. It hurts, it’s stupid. Perhaps I misinterpreted what she said, perhaps I am too sensitive, but when you have been through what I have been through there is still something that can be hit upon and that hurts. I have tried to become stronger” (ibid: 55 and 56).

It seems to me from listening to these stories that the mothers’ most difficult time is when their children are likely to be criticized at school for their lack of adaptation. When the children are doing better at school these mothers are doing better. The younger the child, the more precarious the school situation, the less the mother can help the child to learn, the more sensitive these mothers are.

5.3.12. What about the children?

Hélène says, “I think of all the messages that our children must get. For many of them, there is a vicious circle that is installed at school and at home. Whatever they do, it is negative. It is never enough, never good enough. We have to remind ourselves that many children don’t have friends so they don’t have a support network. It isn’t surprising that they think of suicide, that they don’t want to live anymore. We hear parents telling us that their seven or eight year old children don’t want to be alive anymore, in the meetings organised by the association. The parents ask, “What do you do when your child tells you that his life is not worth living?” (ibid: 14).

Mélanie’s son, Laurent, told her that his life wasn’t worth living. At the age of seven, he tripped over an artist’s table and damaged his eye. The following day at the hospital, he climbed into his mother’s arms. She says, “he said to me, ‘Listen, Mummy, I am worthless. I serve no purpose. I only make mistakes. I want to die. I don’t serve any purpose at all. I make you so unhappy and I blame myself.’” (ibid: 42).

Hélène says, “I’m proud of my son. I don’t tell him often enough. I am a bit of a perfectionist, a bit square. If I could do it all over again, I would work much more on the self-esteem. We are educated like that. Our beliefs say that we should not applaud our children. I think that he wouldn’t have wanted us to anyway. He would have known that we were exaggerating. When he did something that we considered a feat, he could see for himself because he could

compare with what his friends did. He wasn't stupid, so we dealt out the compliments sparsely" (ibid: 12).

Marion says, "If Raoul has a good circle of people around him, people who place their trust in him, and school friends who he gets along with, then he makes enormous progress" (ibid: 57). Marion explained that in fourth grade there were five children who teased him all the time. She asked the school to put Raoul in a class without two of them. He was lucky; none of the five were in his class. "She says, this year he is doing well" (ibid: 57).

Hélène says, "Some of the time we are so preoccupied with the messages that we receive that we don't notice that our children get more, and from us as well" (ibid: 14).

5.3.13. Conclusion: Talking about the experience of sharing stories

I would like to thank these five mothers, Hélène, Karine, Mélanie, Marion and Marie-Jo, for having spent the time with me. Initially they did it to help me understand the discourses about mothers whose children were in difficulty, and had been diagnosed with ADHD.

I also asked them during or at the end of the interviews, what it was like for them to talk about their experience with me.

Hélène says, "I wanted to start with the negative and finish with something positive, but I think it was more mixed up between the positive and the negative. One message overlays another. In the beginning when you tell the story, you re-live the experience. I don't know if you can hear it in my voice. It's like having a flashback, you are in the situation again. We have memorised it. We live it again. We have to relive the messages that hurt us, that made us furious. Even if we can tell them again more serenely, we still experience them again. It's in our skin. Some things you cannot get rid of. You tell yourself that it's over. After a certain amount of time, you can step back and that is helpful. It is the temporality that makes these messages seem negative, but that can change. It depends what we do with them. The resources that we have around us play a role in the messages we receive. Without any support, they are fatal" (ibid: 13).

Mélanie talked about how it was different to talk to me about receiving the prescription for Ritaline. She says, "Now that I am talking to you, I manage to say the things differently. Indeed standing back now, it was not the prescription that helped me, but the listening and the words [the doctor] used" (ibid: 43). Later, she says, "I realize that some particular times, some experiences were really difficult. They left enormous wounds. It is our children who heal the wounds. Now they are healed, except when, in your presence, I talk of these memories. But finally these memories are positive because if I hadn't had to go

through these experiences, perhaps I wouldn't have grown up the way I have" (ibid: 47 and 48).

Marion says, "It has done me good. Perhaps because you are a mother and you know ADHD. I don't need to explain it all to you. You know what I am talking about. It is easier to know that the person in front of me knows what it is like, that it can be like living on another planet" (ibid: 58).

Karine says, "I am happy to share my experiences. I hope that it will give other mothers courage. I am happy to see that someone is looking at the guilt that mothers carry. I find your process very supportive. You see, I think it's a great opportunity to talk about it. Especially as I feel that I have someone opposite me who has experience as well. It is that that is helpful, and it is that that allows be to be 'wide open' because I feel understood, and I am not being judged. That's it. Thank you very much" (ibid: 27).

Here we come to an end of the mothers' stories. I hope that these excerpts from our interviews reflect the situations that mothers find themselves in, whereby they are positioned by others and how they negotiate those positions and their identities. In Chapter 7, under Point 7.5. I discuss my portrayal of the mothers and the experience of interviewing them.

5.4. Klinefelter Syndrome

In this chapter about differences, I introduce you to Klinefelter Syndrome. I have already written about this syndrome in the Prologue. In the first section, I describe the terms related to people who have Variations of Sexual Development, formerly described as intersex conditions in the introduction. To call these people intersexed is to reduce them to being only "intersexed," as happens with many of the labels that we give. I also describe what I would consider a typical introduction to the subject that I experienced during my studies. In the second section, I talk of the fictional works that I have read on the subject of people with these variations, which create some of the myths around these people, in comparison with non-fiction works. And in the third section, I describe some of the challenges that face parents of children born with variations including Klinefelter Syndrome. In the fourth section, I write about the day the endocrinologist told me that Edward had Klinefelter Syndrome.

I have tried where possible to eliminate my use of the term "intersex" in this dissertation, but when I draw on authors who use the terms, I have left them.

5.4.1. Introduction

According to Diamond (2002), "an intersexed individual is one born with physical characteristics that are both male and female." He explains that the variety of intersex conditions is very large, that "even within a single category of intersex there is a great variation." In this very first paragraph on the terminology of intersex, I stumble across the terms "intersexed" and "category

of intersex.” As I mentioned in the Prologue, people who have what I call “an intersex condition” would be considered as having a Disorder of Sexual Development, a “DSD” (Intersex Society of North America, 2006). The term “DSD” is under much debate amongst people affected by such conditions, as it is considered pejorative. The preferred term for these people and many of their associated practitioners is “Variation of Sexual Development”.

The first time I encountered the notion of variation of sexual development was during my first year of psychology studies with the Open University, when planning an attitude survey at summer school in 1998. Our class tutor asked the group to read Gross’s (1992) chapter entitled, *Sex and Gender*, to understand sex typing. My main memory of this chapter was the dizzy spell it procured in me, in particular while looking at the photos taken from Money & Erhardt (1972) and the descriptions of the “case of the Batista Family,” in which a remarkable family where four of the sons changed, without external intervention, from girls into muscular men at puberty (Gross, 1992: 683). I often suffer dizzy spells when listening, reading or even recounting my own experience of illness, operations and related physical suffering. It may well be a learned behavior as both of my parents told us and showed us how uncomfortable they were when having to have an injection or have blood taken. However being the squirrel that I am, I had kept my photocopied version of this chapter. I took this chapter out to read after Edward had been diagnosed in December 2000. My husband, Jean-Luc, did an internet search at the same time and constituted a folder of medical literature. My main reference was the website of the Turner Center in Aarhus, Denmark, which published an article on Klinefelter syndrome. I can no longer find this website.

5.4.2. Lack of public awareness

The ‘general public’, this unknown majority, does not know about Variations of Sexual Development, (VSD), or intersex conditions. They don’t know the word ‘intersex.’ They most probably have a better understanding of the word ‘hermaphrodite’. From having no knowledge to increasing knowledge is the implication of awareness of difference; the unfamiliar, and the strange, but from an external viewpoint. They may be integrating their feelings of ‘strangeness’, feelings of discomfort. Harper writes, “Intersex is more common than another well-known genetic difference, but much more taboo and misunderstood [...] there is great cultural unease about ‘aberrant’ bodies that challenge the certainty of male and female as mutually exclusive, complementary (some would argue preferably heterosexual) and thereby ‘wholesomely’ reproductive” (2007: 25).

People with a variation of sexual development don’t have more knowledge about their variation than the general public. They learn about the variation that is part of them at a particular point in time. In her *Orchids – my intersex adventure*, Phoebe Hart talks about the difficulty of accepting her body with its differences. She was told at the age of seventeen by her mother about her Androgen Insensitivity Syndrome (AIS), and she talks about the difficulty of

living with the secret that she would never be able to have her menses or bear children. The operation to remove her internal, male gonads before puberty was disguised as a hernia operation. Our human capacity to be both subject and object of our scrutiny is difficult for most people in the Western culture. Our obsession with the perfect bodily appearance increases the difficulty that the majority of us have in accepting our bodies the way they are.

The time in which those who are closely involved, either as a person with a VSD or as a parent, learn of the condition from the medical profession and are requested to take action, i.e. decide about medical intervention, is relatively short. Harper writes of her interview with Philip Ransley, consultant paediatric urologist at Great Portland St., London. She writes, “Ransley [...] insists that parents are much more intimately involved and informed than they used to be in these vitally significant first few weeks. But he reasons that it is ‘ludicrous and unrealistic’ to expect the vast majority of parents within two weeks to “assemble the concept of intersex, work their way through it, and come to the rational decision of what is correct for their child (interview 6 September 2005).” (Harper, 2007: 33). There are few VSDs where it is necessary to intervene medically immediately. Most of the medical interventions are to usually to relieve the distress of the parents, and most probably the medical corps. As Solomon writes, “Anomalous bodies are usually more frightening to people who witness them than to people who have them, yet parents rush to normalize physical exceptionalism, often at great psychic cost to themselves and their children. [...] Much gets corrected that might better have been left alone” (Solomon, 2012: 4-5). Legislation in some countries is being considered to ensure that the children are not operated on until they are both able to understand the intervention and to consent to it.

5.4.3. Popular literature constructions

When Edward was first diagnosed, it was difficult for me not to talk about it. As I have said in the Prologue, it was initially a relief to know that there was a reason for his difference. I talked to various people about it and I am sure that my family talked to others about it. An aunt came up to me at a family get-together in August 2003 and asked me if Edward was a hermaphrodite. Edward, like the majority of boys with Klinefelter syndrome, was always considered a boy. There seemed to be little ambiguity about his body, apart from the lack of physical development characteristic of boys at puberty. If my aunt was the only one to openly ask me about Edward, I am sure that a number of people were intrigued about Edward’s condition, and so I found myself receiving books or recommendations for books about people with variations of sexual development. My purpose in writing about these books is that often popular literature displays the myths around subjects, and one of the myths that I would like to address is the idea that a person with a variation of sexual development is on a quest. This idea of quest generally reveals a set of beliefs that the person will find his or her way in this world, and that support is not necessary. These

stories also highlight either the lack of support parents were able to give, or the irrelevance of the support. This individualistic notion of being a lonely hero on a quest seems to indicate that the lonely quest is indeed a necessity, and that parents should not worry themselves for not having provided support.

Of the four books that I present, two are fictional stories, or ‘quest narratives’, whereas the stories written about people who lived are ‘chaos narratives’ (Frank, 1995). In quest narratives, the protagonist sets out on a journey with a purpose to find something. In these stories, it would seem their quest is to find their own sexual identity. Campbell (1995) has written about the myth of the ‘Hero’s Journey’, whereby a person hears the “call to adventure” which turns into a quest. By portraying people in this way, it seems to me that we reassure ourselves that this was the person’s destiny, and that it could not have been otherwise.

The second book I read was Eugenides’ book, *Middlesex*, which won the Pulitzer Prize in 2003, and describes the story of Calliope, a second-generation Greek girl in the States, who has 5-alpha-reductase deficiency syndrome. Eugenides writes, “I was born twice: first, as a baby girl, on a remarkably smogless Detroit day in January of 1960; and the again, as a teenage boy, in an emergency room near Petoskey, Michigan, in August of 1974. Specialized readers may have come across me in Dr. Peter Luce’s study, ‘Gender identity in 5-alpha-reductase pseudohermaphrodites,’ published in the *Journal of Pediatric Endocrinology* in 1975. Or maybe you’ve seen my photograph in chapter sixteen of the now sadly outdated *Genetics and Heredity*. That’s me on page 578, standing naked beside a height chart with a black box covering my eyes” (Eugenides, 2002:3). Having been determined a girl at birth, Calida is taken to see Dr. Luce at the age of 14 at the Sexual Disorders and Gender Identity Clinic in New York. The character of Luce is fashioned after Dr. Money, the psychologist famous for his theory of neutrality (Money and Erhardt, 1972). I will describe the theory of neutrality in the next part on academic literature. “Luce argued that gender is determined by a variety of influences: chromosomal sex; gonadal sex; hormones, internal genital structures; external genitals; and, most important, the sex of rearing” (Eugenides, 2002: 410). Calida, left alone in Dr. Luce’s office, reads his report and realizes that he is lying to her and her parents, and that he plans to operate on her genitals. “I had miscalculated with Luce. I thought that after talking to me he would decide that I was normal and leave me alone. But I was beginning to understand something about normality. Normality wasn’t normal. It couldn’t be. If normality were normal, everybody could leave it alone. They could sit back and let normality manifest itself. But people – and especially doctors – had doubts about normality. They weren’t sure normality was up to the job. And so they felt inclined to give it a boost” (Eugenides, 2002: 446). Calida runs away, leaving her parents in New York City, and ends up in San Francisco where she/he becomes part of a ‘freak show’ in order to earn a living, while staying with a colleague, Zora. She/he decides to read everything available. “I read everything Zora gave me, trying to educate

myself. I learned what varieties we hermaphrodites came in. I read about hyperadrenocorticism and feminizing testes and something called cryptorchidism, which applied to me. I read about Klinefelter's Syndrome, where an extra X chromosome renders a person tall, eunuchoid, and temperamentally unpleasant" (Eugenides, 2002:494-5).

Annabel, written by Kathleen Winter and published in 2011, is the story of Wayne/Annabel, born to Jacinta in a North Eastern state of the United States. Jacinta's husband, Treadway, a trapper, decides that the baby should be brought up as a boy although he has ambiguous genitals. The story describes how the parents, the child and the neighbour, Thomasina, keep the secret of Wayne's hermaphroditism as he grows up. Although I find the depiction of Wayne as a "true hermaphrodite" and the episode where he is found to have impregnated himself as sensational and hard to believe, there are parts of the text that appeal to me. One of these parts is the following, "But when you are the mother, you take it in stride. You take albino hair in stride, when you are the mother. When you are the mother, not someone watching that mother, you take odd-coloured eyes in stride. You take a missing hand in stride, and the same with Down syndrome, and spina bifida, and water on the brain. You would take wings in stride, or one lung outside the body, or a missing tongue" (Winter, 2011: 23).

At the age of 17, Wayne leaves home to go and live in St. John's, leaving his depressed mother, who has become increasingly depressed, alone while his father is away for the winter months. He decides to stop taking his medication, and to let his body develop. He finds himself an apartment and a menial job. He makes a friend, Steve, in whom he confides. Steve understands that Wayne has had a sex-change operation and tells the local bully, Derek, who attacks and rapes Wayne with his buddies. Wayne writes to Thomasina and she, in turn, tells Treadway who comes to visit. Treadway makes a gift of his savings to Wayne, and accepts his son's difference. Wayne uses the money to start studying engineering at university, where he finds a place where he fits in. "The other thing Wayne noticed was that among the students he did not feel out of place because of his body's ambiguity, as he had felt on the St.s of downtown St. John's. Many of these students looked to Wayne as if they could be the same as him: either male or female. There was not the same striation of sexuality that there was in the ordinary world outside a campus. There were girls who looked like he did, and there were boys who did too, and there were certainly students who wore no make-up and had a plain beauty that was made of insight and intelligence and did not have a gender. He felt he was in some kind of a free world to which he wanted to belong, and he wondered if all campuses were like this" (Winter, 2011, pp.455-6).

In these two fictional stories of Eugenides and Winter, we have the quest narratives of two young people who venture from home in an attempt to find themselves. Both of them encounter other people who tell them they are freaks.

The non-fictional story written by Noelle Châtelet, *La tête en bas*, was told to her by sixty-year old Paul, born Denise, in France. The book was given to me by Karin, a long-standing client and friend who knew about Edward's syndrome, in 2003. I read it again in 2011, reminded by the book *Annabel*.

Denise relates that from her earliest memories she was a "tom-boy." The name of her particular variation is never mentioned. The story focuses on Paul/Denise's difficulties with her body. Her parents seemed to be well aware and sympathetic towards their daughter's "tom-boyishness" from an early age. She has a school friend, Geneviève, in whom she confides and who accepts her difference. In spite of their acceptance, Paul /Denise calls herself a "monster." Paul/Denise says, "Je suis un monstre. J'ai quinze ans et je suis un monstre. Bien sûr, personne ne le dit: ni ma mere, ni mon père, ni Geneviève, ni même le médecin qui l'avait décelé dans mon sang, mais moi je le dis au miroir de la salle de bains qui seul parle vrai, qui seul me connaît nu. Sous la lumière crue du néon, je vois bien que rien ne va avec rien, le haut avec le bas, le bas avec le haut, à cause du jardin fou où tout a poussé n'importe comment. A la foire, les gens paieraient pour me voir, pour voir le monstre" (Châtelet, 2002:64). Denise/Paul has compared herself to her girl friends and found that her top (her breasts) does not match her bottom (her masculine genitals), and calls herself a monster. No one counters that designation.

Denise/Paul hears about her "hermaphroditism" in a biology class at university and realizes that "it is her body" that is being described, and shortly after is interned in a mental healthcare institution called "la Maison" where she stays for a long time until she is "at peace". During this time she hears the doctor's formal description of "virilization". At the age of 40, Denise's request to have her breasts surgically removed is fulfilled by a doctor and she becomes Paul.

The book *Herculine Barbin*, published by Michel Foucault in 1980, consist of the memoirs of Adélaïde Herculine Barbin, called Alexina, found after her suicide in February 1868, the medical and press reports and the story "A scandal at the convent", written by Oscar Panizza. In his introduction, Foucault writes, "When Alexina composed her memoirs, she was not far from her suicide; for herself, she was still without a definite sex, but she was deprived of the delights she experienced in not having one, or in not entirely having the same sex as the girls among whom she lived and whom she loved and desired so much. And what she evokes in her past is the happy limbo of a non-identity, which was paradoxically protected by the life of those closed, narrow, and intimate societies where one has the strange happiness, which is at the same time obligatory and forbidden, of being acquainted with only one sex" (Foucault, 1980: xiii).

Alexina was brought up as a girl, sent to boarding school and won a scholarship to become a schoolmistress. Assigned to a convent boarding school, where she is appreciated by pupils and management, she becomes lovers with Sara, the niece of the Mother Superior. When they are caught asleep and undressed in the

same bed, Alexina's body appears to be very masculine. She is forced into a medical examination and is described as being more than male than female. She is legally declared male and renamed Abel shortly after in 1860, following more examinations by both the medical and legal profession. In She writes, "So, it was all over. According to my civil status, I was henceforth to belong to that half of the human race which is called the stronger sex. I, who had been raised until the age of twenty-one in religious houses, among shy female companions, was going to leave that whole delightful past far behind me, like Achilles, and enter the lists, armed with my weakness alone and my deep inexperience of men and things. Dissembling was no longer to be thought of. People were already talking in whispers. The little town of L. was aroused by this extraordinary event, which by its nature excited criticism and slander" (Barbin in Foucault, 1980: 89-90). Alexina/Abel could not stay in her hometown and she left for Paris where she committed suicide at the age of 30. In Dreger (1998) there are pencil sketches of Alexina/Abel's genitalia that were drawn while she was on the autopsy table. Even after her death, her body invoked more curiosity and attention than compassion.

All of the books evoke a period of time when the person removes him/herself from their familiar environment and contact with their parents, depriving themselves of support. Parents are depicted as not being able to provide support as well. In *Châtelet*, the parents are seen as been unable to avoid their child's psychiatric internment in spite of being very accepting. In *Eugenides*, the parents are shown to hand over their daughter to the doctors, and she runs away. In *Annabelle*, the only person who accepts and supports both the mother and child leaves the area and becomes unavailable. There is no one to share their secret. In the non-fictional stories, both Denise/Paul and Alexina/Abel suffered from being different, and suffered anguish and depression. That was Edward's experience as well. I wonder if it has to be like that.

5.4.4. Professional and academic literature on variations of sexual development

Money's work on infants and children with variations of sexual development started in his early days of medical studies leading to his claim that a child's sexual identity was formed by the age of three. Harper describes Money's "theory of neutrality" (Money & Erhardt, 1972), "Money believed that for the first two years of life humans have such a neutral and unformed gender identity that our brains are malleable. That is, a baby could be 'trained' to believe itself male or female" (Harper, 2007: 47). This notion has not only led to numerous medical and surgical interventions on infants and children, but it has been quoted as proof that sexual or gender identity is a social construction. Psychoanalysts, Eichenbaum & Orbach, write, "[Money and Erhardt's] work shows very clearly that the ideas we hold about femininity and masculinity relate to the cultural practices of a given society and not to biological imperatives" (1983: 23-25). The cultural practices of a given society do, indeed,

form the ideas that we hold about femininity and masculinity, and our attachment to the binary distinctions between men and women. However, we cannot ignore that there are, what we call, biological or bodily imperatives that are not limited to cultural practices. Money based much of his research on the case of David Reimer who was assigned to female identity following a medical accident in which his penis was destroyed (Diamond & Beh, undated). The current belief was that “life as a male without a penis would be intolerable “ and “that any individual without a penis should be raised as a girl.” Money’s lack of long-term follow-up is heavily criticized today. David Reimer did not adjust happily to life as a girl, and threatened to commit suicide at the age of 14 unless he was able to live as a male, which he did until his suicide at the age of 38 (Diamond & Beh, undated; Diamond, 2000). Today Diamond, perhaps one of the most well-known experts on variations of sexual development, argues that parents and doctors should not be allowed to intervene surgically or medically without the consent of the child. The recommendation is that any form of surgery and hormonal intervention should not take place until puberty when further feminization or masculinization can take place. Some of those who have had medical intervention without their consent, as children, are quoted in Harper who concludes, "Anecdotal and clinical evidence is amassing that indicates substantial risk with such surgery of loss of erotic sensation and orgasmic function, infertility, life-long urinary pain and dysfunction, pelvic infection and endocrine malfunction, and psychological trauma" (Harper, 2007: 46).

For the majority of parents of a newly-born infant with visually obvious ambiguous genitals, the pressures are immense. The first being, how does the parent answer everyone’s typically first question: is it a boy or a girl? There are many questions that parents have, and the way doctors answer may be extremely influential on how they come to be with their child. Karkazis writes , “parental adaptation to the condition may be the most important factor for determining the child’s quality of life; the question remains to what extent encounters with medical caregivers and current treatment foster their adaptation or hinder it.» (Karkazis, 2008: 178-179).

For many parents, the variation of sex development of the child is not visually obvious and it is later that they and the child find out. With Klinefelter’s syndrome, unless it was a prenatal diagnosis, most men find out much later in life. Harper writes that Klinefelter’s syndrome is an adult condition as the syndrome’s symptoms only appear with puberty, and therefore the majority of men with this condition only find out when their puberty is delayed, or when they cannot have children with their partners (2007: 146). Edward was diagnosed in December 2000 because of delayed puberty, something that embarrassed him because of the teasing he experienced at boarding school.

Klinefelter, it would seem, is a particular form of the variation of sexual development, sometimes called XXY. There are women who have XXY chromosomes, who differentiate themselves from being male. Certain

Klinefelter support groups insist that men with Klinefelter's are neither intersex nor female (Harper, 2007: 156). Harper writes about the desire to normalize XXY and other variant karyotypes, or to reassure the men are essentially male and that they can be cured by hormone replacement therapy (ibid: 159). In the quest to render this group of men more masculine, as to fit in with the stereotypical ideal of masculinity, they are encouraged to take synthetic testosterone and have mastectomies, if they have developed breasts. Dr. S., the endocrinologist, who diagnosed Edward said that the only problem with this syndrome was sterility. Otherwise, he claimed, Edward's life would not be affected. In Parker and Parker (2002) they advise telling the child with Klinefelter's syndrome at the age of roughly 12, if he is emotionally mature enough, that he is likely to be infertile. "Parents should stress that neither the X chromosome nor the infertility associated with it mean that he is in any way less masculine than other males his age." They also recommend telling him that he would be able to adopt a child if he is infertile (ibid: 15). How parents tell the children about their variation is another challenge, and whether they are helped by supportive professionals. David (Harper: 159) was described by the doctor as 'a deficient male'. Edward recently told me that Dr. S., the endocrinologist, told him that he was a 'mutant'. I didn't know what to say to Edward, but my husband, Jean-Luc, seemed to be more at ease. He told Edward that the synthetic hormone replacement would give him what nature was not giving him in order to make him go through puberty. He also told Edward that Edward could do like he had done, that is to find a woman with two children and become a step-father.

Diamond also writes that "males and females who have alterations in sex chromosome number are at increased risk for behavioural and learning disabilities" (Diamond and Watson, 2004). Bruining et al (2009) write, "impairments in the areas of communication, socialization, and disorganized behaviours may be present in boys with KS. This makes them liable to isolation and emotional problems that may require guidance and treatment." Edward was diagnosed as having Attention Deficit and Hyperactivity Disorder (ADHD), and other learning disabilities when he was ten. In 2001, our family physician said that Edward was the third boy he had met in one year who had Klinefelter's syndrome and who had been originally diagnosed with ADHD. Many descriptions of boys with Klinefelter's syndrome do not fit Edward. He is not shy, retiring, and quiet with verbal communication difficulties. He is outgoing, voluble, and expressive. "Only 10% to 25% of the expected diagnoses of KS (Klinefelter's syndrome) are made before puberty [...] we recommend that all children with KS be examined by a child psychiatrist, which may prevent delay of treatment and may possibly protect these children from adverse environmental influences" (Bruining et al, 2009: 869). They also recommend that all children with behavioural and cognitive/learning problems should be screened before the age of ten for Klinefelter's syndrome. Under Point 5.4.6.1, when I describe our paediatrician's reaction to the endocrinologist's diagnosis, we can understand that the syndrome is considered rare. Harper

(2007) says the number of men with Klinefelter's syndrome is considered to be two in every thousand. Bruining et al (2009: 865) write that is the most frequent chromosomal aneuploidy with a prevalence of 1 in 700. Given the frequency, I wonder how it comes to be that I have only met one other mother with a boy with Klinefelter's syndrome. I write about our conversation under Point 5.4.8.

5.4.5. Reflection and conclusion

The first time I talked to another mother whose daughter has Turner Syndrome, a chromosomal variation of sexual development, she insisted that her daughter had "a real syndrome, a genetic syndrome, not like ADHD." That made me think that there was a pecking order amongst mothers about their children's diagnoses although I imagine that the pecking order is also operationalized through the medical discourse. Do you take Edward's story more seriously because he has Klinefelter's syndrome? If he had "just" ADHD, would you have less compassion or interest in our story?

I don't know how life would have been for Edward and for me had we known about Klinefelter's syndrome earlier. It would have been different. Would I have been alleviated of the guilt and shame I sometimes felt about my son's behaviour?

5.4.6. My experience of having a child with a Variation of Sexual Development

In this section I relate my account of the day of Edward's diagnosis with Klinefelter syndrome and review this experience through the method of Voice Dialogue, which I introduced in Chapter Three, under Point 3.8.3.

5.4.6.1. The day of Edward's diagnosis

In December 2000, I talked to Dr. M., our pediatrician, about Edward and Beatrix's late physical development. A few years earlier she had taken x-rays of their wrists and hands, and told me that they were about two years behind their age group in their physical development. She told me to take them to see Dr. S., a pediatric endocrinologist at a private hospital outside Geneva.

My memory is of one visit, but the family calendar says that there were two consultations. On December 7, I took the two children. I stayed in the room with Beatrix while he examined her first. He was an older man, perhaps an elderly man. He was short, very white haired and had the kind of crinkly skin of elderly people. He was working most probably on a part-time basis. He was very courteous. He was very respectful of Beatrix. He told her that she seemed to be in good health and there was no reason to worry. He then called Edward in and I left the consulting room. He examined Edward.

According to the family calendar, I returned on December 21 with Edward. He said it would be necessary to do a blood test to confirm his diagnosis of Edward. He was, he said, 99% sure that Edward had a syndrome called I couldn't

retain the name. He repeated it for me. I took out a piece of paper and wrote it down, “Klinefelter”. He corrected me, it was “Klinefelter,” and it only meant that Edward would be sterile. He said we would have the results in a month, and we scheduled an appointment for January 18.

We left the clinic, got into the car and started driving home. Edward said to me, “Don’t look so sad, Mum, it’s my body, not yours”. I was thinking about the signification of what we had just heard, what did it mean for Edward’s life? Would he have a normal span of life? Were there other medical implications that we didn’t know about? I could hardly remember the name, let alone anything else he said. We had to stop off at the shopping mall to go to the telephone shop. I called the pediatrician and told her that we had just come from Dr. S.’s and gave her the diagnosis. She said to me she would call me back. While we were at the mall, she called back. She said that it was not her fault that she had not diagnosed this. I don’t remember what else she said, but it seemed clear to me that she was not worried about what this diagnosis would do to Edward and me, she was worried that she would be blamed. She was worried about herself. I said to her something along the lines that I was not calling to ask about her, I was calling to tell her about Edward. She was saying that it was such a rare illness, that she hadn’t thought about it. I said to her, I am not blaming you. I just want to talk about Edward. And on she went. Eventually I told her that I didn’t want to talk to her anymore. This is perhaps what she was expecting, but it wasn’t because I blamed her. Weeks later, I got an invoice for that telephone call for 27.- Swiss francs. I remember debating whether I should pay it, and thought that if I didn’t pay I would be keeping the relationship open. I paid it.

5.4.6.2. Reflection

In the following section, I demonstrate the voice dialogue method that I described in Chapter Three, to reflect on the events that happened on that day of diagnosis. The left and middle columns contain the conversation between my two voices, the questioner and the responder. The right column was added afterwards to allow Sheila McNamee, my PhD advisor, to respond to the conversation as it developed. Her remarks are in italics. The writing and subsequent exchange took place in May 2010.

This extract shows how my voices are focused on my narrative, my interpretation of events, as the ‘most truthful.’ It also shows how the conversation evolves to imagine myself listening to doctors’ voices, and despite having been through the experiences in the way I chose to narrate them, that is still a possibility.

Sheila’s remarks demonstrate how social constructionism would remain open to other perspectives and interpretations in spite of the experiences described.

<u>Questioner</u>	<u>Responder</u>	Sheila's remarks written after the initial conversation between the questioner and the responder
What's going on?	I am saying to myself, "why did you cut out Dr M.?" I mean it might have been helpful to have continued consulting her.	<i>Interesting that you start here! I wanted to start with the "matter-of-fact" style in which the specialist told you about Edward's diagnosis!! "It's not terrible...only sterile...."</i>
It sounds to me like you are hurt?	It was hurtful to hear her bleating about what her role was in this situation, inferring she should not be blamed. But we needed support. We were sitting in that car not knowing what had hit us. Edward was looking at my face, with that way that he does, taking the cue from my expression. And all that woman could think of was herself.	<i>Yes. This is also amazing but what is more amazing is the nonchalant treatment of the entire thing! Your son has just been diagnosed (probably) with a syndrome you have never heard of and the doctor makes no effort to explain, answer questions, etc....he simply dispatches you out into the world (the mall, of all places)!</i>
And what else comes up?	And then of course I think I could go back and discuss it with her as part of my inquiry. I think I would hit her.	<i>You won't hit her. You are actually being generous and kind by offering an opportunity to hear her story and let her hear yours (now).</i>
You would want to inflict some pain on her?	I would want to reciprocate in inflicting pain. I would want to tell her how much we have suffered, and how useless she was. Jean-Luc's point is that the doctors, her included, were incapable of being able to diagnose Edward's syndrome, and yet it is so common. Some research that	

	it occurs in 2 out of 1000 men.	
So what do you think? Is she incapable or incompetent as Jean-Luc says? Do you condemn her?	I don't blame her for not being able to diagnose it. There were many doctors who had seen Edward and had not diagnosed it. She was no more incompetent than others that were consulted. Yes I agree with Jean-Luc that if it is so common then it should be known about.	<i>But doctors are not gods. They have their own specialty areas and a GP is just that: general practitioner....with no particular specialization. Pediatricians fall into this category. I don't think there is any reason to believe that any doctor outside of a specialist would be able to diagnose this or even think of it as a possibility.</i>
So what was it you wanted from her?	Some support. I wanted someone I could talk to, who was on my side, on Edward's side, who could tell us what to do next. She had been helpful when we diagnosed Edward as having ADHD, she sent us to the educational psychologist, and she prescribed Ritalin.	<i>Here's my guess. I bet she had to call you back b/c she had to look up what Klinefelter's syndrome was! She was probably so intimidated by the diagnosis that she immediately felt defensive (not in relation to you but in relation to the endocrinologist). By the way, I don't mean to be taking "her side." Just offering a different read on things.</i>
Is that helpful? I mean prescribing Ritalin.	She did then as good as she could with the information that she had. She was always the person I would refer to first of all, and she would send us to consult other doctors, but she was our reference point.	
So you didn't expect her to be	No I don't think I did. I expected her to be the person with whom I could discuss	<i>Perhaps Klinefelters was way beyond her capacity for discussion and</i>

THE expert?	things, get her medical point of view. I wanted her to manage the case – is that what you call a case manager? I wanted an intelligent, caring medical doctor who could talk through things with me, and perhaps stand up for me when other doctors were not been helpful	<i>support....perhaps a total unknown for her.</i>
And instead you found that she was in another dynamic?	Yes now that I think about it. She was in another dynamic. She was into the game of “who’s to blame? I don’t want it to be me” and she couldn’t come into the position of “caring, supportive medical doctor”. It is strange because in Switzerland we don’t take doctors to court like in the States and in the UK. I suppose she could have been charged with negligence elsewhere, but that was so far from my mind.	<i>I’m liking my story of embarrassment better than the story of cold-heartedness or incompetence. Not that my story is REAL but it allows me (if I were you) to engage with her in a more productive way.</i>
Would you like to ask her for her opinion?	Now? Go back to her and ask her for her opinion. I would have to be my best self to be able to do that. That would be an incredible challenge. I wonder if she has retired. And would she charge me for that?	
You are always so funny?	Being funny, having a sense of humor is what keeps me going. It is one of my most important voices. It is the voice that says, “if this were funny, what would be funny about it?” It gives me another	

	perspective.	
Yes and we know what is said about that.	It is a coping mechanism!	<i>Or a use of a different conversational resource that allows you to construct a different pattern, different understanding. Do we have to call it a coping mechanism?</i>
<i>There was an exchange here about the ability to laugh, and situations where laughter seemed to be a helpful response.</i>		
	You would never want a social assistant to see that people can see the funny side of their predicament. They would deny you support. You can just hear the uptight assholes saying, "Well it is totally inappropriate to laugh about it. And I will wipe that smile off your face. I will not recommend that you get any financial support in my report."	<i>Maybe what you have going here is a critique of healthcare (training). Why would any health professional tell someone to stop laughing??</i>
Hey, where did that come from?	Well that was my reality of social assistance and medical support. If you can still laugh, then you don't get any help. We only help the miserable sods in this world.	<i>Do you really think so? Sad thought.</i>
You know I do think you should check out these voices, these discourses that you have with	So that they could explain to us that we are wrong. "You might have felt that, but that is not what we said. You see, you are slightly paranoid, psychotic, neurotic or	<i>Good suggestion by questioning voice. But I don't think they would necessarily call you psychotic or neurotic. Maybe you are the one who</i>

social assistants and medical people.	<p>whatever, because we would never say such a thing.”</p> <p>And then we would feel so stupid. So not only would we not get support, but then we would be told that we are stupid for not getting it “right”.</p>	<p><i>is unwilling to collaborate with health professionals? Maybe you have a predefined script for them and there is nothing they can do to show you a different script? (Just provoking you here)</i></p>
Well this voice of ours sounds a little angry too.	Oh yes and it is definitely not ok to get angry with a medical doctor or a social assistant. That could get you immediate lock-up in an institution.	<p><i>I understand, particularly given your experience with Edward, why you say this but....you seem absolutely certain that your narrative is the correct narrative.</i></p>
It sounds like a Catch-22 situation.	The famous double-bind. Don't try to feel better about your disastrous predicament because you will cut yourself off from all support.	
Shall we leave it at that for the moment?	Yes, but I do think we need to summarize here because I feel we are trying to run away from a painful subject and that it is not going to be helpful.	
In recounting the day that Edward was diagnosed, we managed to surface some of the different voices or discourses that were helpful and not helpful to us.	<p>We found that it is not useful for the medical profession to try to avoid blame, or to even get into that dynamic of blame, because by doing this they are drawing the attention onto themselves, and not focusing on the person's immediate situation and needs.</p> <p>We firmly believe that the notion of blame is more difficult to discuss in counties where a medical doctor could be held legally</p>	<p><i>But maybe she was not trying to avoid blame; she was trying to avoid humiliation by a professional colleague (endocrinologist). I still am not convinced that she was incompetent or that she feared that you would see her as incompetent. It is not her territory; not her area of expertise. Even if it is not such a rare syndrome, how many people know about it? Because she is a doctor she</i></p>

	<p>responsible for a mistake, an omission, a lack of competence.</p> <p>Our Western way of looking at problems to try to identify cause and effects is a way of assigning blame to a person, or an object (which can be the same thing).</p> <p>In a situation where the professional person has not made a correct diagnosis, or failed to make a diagnosis, as in this situation, that person should, in an ideal world, be able to deal with the relationship in all its facets. We would imagine the relationally responsible professional being able to understand that there are two issues at hand: 1) the continuation of support considering the new information, i.e. the diagnosis and 2) the responsibility of the professional for her competence in diagnosing. It is illusory to think that they can be separated out, the ongoing conversation will contain both issues. However, it would be a very skilled performance to achieve supporting the other person and taking responsibility for incompetence which has caused prejudice to the person.</p>	<p><i>should know? Doctors can't possibly know everything and this is not so common as to be an ordinary diagnosis in a pediatric practice.</i></p>
	<p>Furthermore, we found that we were looking at how</p>	<p><i>Seems to me that it was the endocrinologist who was</i></p>

	<p>people deal with “bad news” or a diagnostic. In the above situation, we find the person (i.e. Kate) who lacks the medical knowledge to really understand 1. the actual medical description of the physical functioning and 2. the implications of the diagnosis and possible treatment. In this situation, the person sees that she often has a self-derisive discourse, or the “funny side”, which leads to a respite or a decrease in tension. This led us to discuss the impact on professionals of her reaction, and the implications of possible ways of reacting to her, especially in a negative or punitive sense.</p>	<p><i>deficient in care and support.</i></p>
<p>Could we summarize the different voices or positions that we came up with during this writing?</p>	<p>1. The main piece of text with the description was written by our “trying to be factual” voice. This voice is concerned about the description of a reality as seen by one person. So she tries to be more flexible. For instance, there was a debate about whether to write “I never spoke to Dr M. again” because the words implied that it was by sheer strength of will or belief, that I never spoke to her again, perhaps even when Dr M. tried to get in touch with Kate, which never happened.</p>	<p><i>The missing voices: those alternative stories of the medical professionals. How is it that you are unable to harbor those voices as well?</i></p>

	<p>2. In the following discussion, we had the “hurt” voice. This voice precedes the angry voice, and it is interesting to note that for some psychotherapists anger is seen as part of the “hurt”. It serves as a protective mechanism.</p> <p>3. After that, we had the “isn’t that funny?” voice which could be seen as a coping or defense mechanism, but is used skillfully by Kate to help herself deal with what is going on. The impact of this voice on those who could provide social and medical support is taken into consideration.</p> <p>4. There is also an “angry with social assistants and medical doctors” voice. This voice did not elaborate any further.</p> <p>5. There is also reference to the “depressed” voice that Kate has experienced. This voice claims that it is a temporary state, and not an overwhelming illness.</p>	
So five voices, five different perspectives or discourses.	This is a clear demonstration that in any conversation, we refer to the multiple voices that we can draw on. There is a sixth voice which is the voice “that asks questions” in this work, which invites reflexivity in an ongoing	<i>Yes. And this would be the place to introduce Kate’s alternative voices of the doctors.</i>

	sense. It is this collaborative, reflexive inquiry between voices or discourses that allows new meanings and understandings to arise from material that has been storied in a particular way, and no longer accessed.	
What has changed through this discussion?	We have a certain insight into potential positions of the pediatrician. We could ask ourselves the questions, “Did she ever want to know what happened to Edward?” or “Did she ever reach for the phone, and if she did, what stopped her? What does medical professionals’ discourse say about contacting patients?”	<i>You told her you never wanted to talk with her again. Was she being respectful?</i>
And what does that do for you?	It opens up another line of inquiry (a word we prefer to research. When we talk about research, there is an almost physical feeling of annoyance). And that inquiry would focus on how medical doctors, who are not under any obligation to have a supervisor as do psychotherapists, deal with giving “bad news”.	
And how would that be helpful to you?	It would help me see them as struggling human beings, and be more compassionate towards them, which in turn would allow us perhaps to continue a conversation. It would make me a richer human being.	<i>Excellent!</i>

The above dialogue shows how I was, and still am to some extent, populated by various parts of me that seem to each have their own opinions. This seems similar to what Karine (Point 5.3.5.) described as the various reactions towards the teacher. There are other potential voices that could be integrated, such as the part of me who thought we should continue to consult Dr. S. That voice is the compliant patient or the compliant mother of the patient.

The most information on Klinefelter's syndrome that we received was through Jean-Luc's internet search. He downloaded all of the medical research literature available, printed it out and read it during our December vacation. Intermittently over the years, Jean-Luc and I have read newly available literature. In Chapter Six I write about how "Edward's Mother" persuaded him to consult an endocrinologist because of the risk of osteoporosis, which led to him having a hormone substitute. When I started my dissertation, I started my inquiry into representations of Variations of Sexual Development. This has led to working together with a group of professionals as I describe in the next section.

5.4.7. Working together with professionals

Although I met Dr. Michal Yaron personally in 2009, I did not know that she had a specialization in the medical treatment of children with Variations of Sexual Development, and that she was based at the University Hospital of Geneva. We started talking about the subject in 2010 and she told me about the Intersex Society of North America (ISNA)'s Handbook for Parents (2006). I read it and felt so happy and sad; happy that such a book has been written and sad that I didn't have this book to read in 2001.

In Chapter 6, on *Thoughts from fellow parents and from adults with DSDs*, I read Lynnell Stephani Long who wrote, "But if I had one wish, this is what I would wish for: I wish my mother had asked more questions, and done some research on her own. I wish she hadn't taken the doctors for their word, and I wish she had listened to me when I told her what my desires were. I wish she was told that her child being intersex does not reflect on her as parent. Sometimes children are born different than how we have our hearts set. Unfortunately, she put all of her trust in the doctors at the University, and prayed they could turn her 'son' into a male. Maybe with more knowledge, patience, and understanding, my mother would have had the tools needed to be a great parent" (ISNA, 2006: 90).

Michal introduced me to a group of doctors and a lecturer in social sciences, led by Dr. Blaise Meyrat, who collaborate on an elective course *Ni fille ni garçon: Anomalie ou difference* (Neither girl nor boy: anomaly or difference) for third year medical students at the Cantonal University of Vaud (CHUV), in Lausanne in June 2011. I talked to the students about my experience with Edward in March, 2012. One of the doctors is Dr. Ariane Giacobino, a geneticist at the University Hospital of Geneva. She invited me to visit the genetics research department in the beginning of September 2011. She introduced me to a lab

technician who was compiling a karyotype on her computer. I watched as she sorted out the pairs of chromosomes, and could see that there were two chromosomes under the X. The karyotype belonged to a girl. Ariane also showed me the meeting room, “the sad place where they give people their results”. The support group starts to become a possibility, and as of February 2013, I am attending the course as an observer to improve my medical knowledge, and to meet doctors who are considered experts. From my perspective, I am also evaluating the empathy of the doctors, so that I can recommend them to parents in the future.

5.4.8. Meeting other mothers

I meet Fabienne (a fictitious name) for lunch mid-September 2011. I have already mentioned her under Point 5.4.5. We were introduced to each other by Karine, who was interviewed by me. Fabienne’s daughter, Gabrielle, has Turner syndrome. She has only one X chromosome. She was about 16, at that time, and has an older brother. Fabienne chose to have a pre-natal diagnosis during her pregnancy. Her two parents are doctors. When she was given the diagnosis by Dr. P., a geneticist based in Lausanne, he gave her and her husband ten days to decide whether to keep the foetus. Because the majority of Turner girls are naturally miscarried, they have a reputation of being determined to live. Fabienne decided to continue her pregnancy, but was tormented by dreams of giving birth to a monster. Her daughter was born without the typical physical signs related to the syndrome, and was started on growth hormone injections from the age of 4. The Disability Insurance refused to pay for the injections because she did not show the clinical signs. I had imagined that Fabienne’s life was different, her burden easier with the knowledge and support that she had, and all my assumptions are proven wrong. She tells me of her difficulties to accept this child. However, when she talks of her daughter as she is today, she beams. Fabienne attends the support group in the Swiss-French area for Turner syndrome. She tells me that when she sees how short the other girls are, those who did not have growth hormone injections, she tells me she is lucky. She says embarrassedly that she can see that the other mothers are jealous of her, and she understands that.

Dr. P. put me in touch with Sandra (fictitious name) and we talked for almost an hour over the phone in November 2011. It was the first time for both of us to talk to another mother of a boy with Klinefelter syndrome. I asked her if we could meet to talk about creating a support group. She told me that she would prefer if we met at her house, at a time when her son is at school, because she was worried about being overheard. She said, “In cafés there are always ears listening in.” She also knew through pre-natal diagnosis that her future child had Klinefelter syndrome and decided not to terminate her pregnancy. She and her husband decided to keep his syndrome a secret, and Jerome was told, at the age of 16, that he has a mosaic form of Klinefelter. She says to me, he is perturbed and angry since she told him, and doubts whether she did the right

thing. She does not want to be part of a support group for other parents, but when I ask her if I can interview and publish her story, she agrees, as long as her real identity is not revealed. When I tell her about Sebastien Keller's (Joye, 2012) idea of being available for future parents who have to make the same decision she had to make over seventeen years ago, she agrees to that possibility.

These conversations with other mothers remind me that my experience and my hopes cannot be generalized.

5.5. Conclusion

In this chapter I have written about the mothers' experiences of the coordinations they have had with professionals. It is within these coordinations that we can understand the patterns or rituals of communication that are underpinned by expectations, values and beliefs of both parties. This is the site of conflicting discourses, where mothers' expectations of professional support are not always fulfilled. There are also examples of coordinations that the mothers have found helpful, and that should be regarded as possibilities of different ways of going on together. In breaking the patterns of communication in the coordinations they had come to experience as negative, they have shown signs of resistance and positioned themselves differently. These examples may serve as guidelines to mothers who are looking for ways to re-position themselves.

I have also written about Klinefelter Syndrome, in particular, and Variations of Sexual Development in general. From my perspective, it is important to increase general public awareness about these variations, which, in turn, will increase the tolerance and acceptance of society, and that, in turn, will make it easier for parents to resist the pressure for medical interventions at an early age. However, we also have to support parents individually with the practicalities of life with a child with a VSD. Doctors seem to forget that a medical appointment where advice is given quickly is but a brief moment in the course of time. We have seen how parents who are worried about the future of their children can be vulnerable and prone to select the negative messages to pay attention to, or to hear them as criticisms. The way doctors communicate with their patients and their parents is vital to encouraging and empowering parents whose children are different.

And lastly I have written about the episode, a day of crisis, in which I experienced a lack of support, and how I am enjoined to step out of that perspective and to be able to see that professionals are not only unsupportive, but are also multiply served.

Chapter 6: The on-going project of identity construction

In this chapter I present a more personal account of my multiple voices, my polyphony of voices, constructed in relationship with others. The accounts of my internal voices demonstrate the internalization of others, including academic perspectives, that have helped to construct the various positions that I can occupy. The academic discourses value other forms of expression of motherhood, and ones that I personally find helpful in both narrating my project of identity, and in negotiating my identity with others whose perspectives I find restrictive, if not oppressive. This is what Burr (2003) reminds me of, that I can choose other discourses about motherhood that are more helpful and useful to me. This piece of work hopefully depicts how identities are created within social relations, and that any one description does not take into account the rich potentiations of polyphony (Gergen, 2009).

6.1. Accounts of my voices – how Edward’s Mother came to be

“I am because you are” is printed on a greeting card bought in a small shop in Portsmouth, New Hampshire. Beneath the statement is written, “an African proverb.” I am here today writing for you. You allow me to express what I want to say today. What I am going to tell you today is a story of how the voice that I call “Edward’s mother” came to be. It is one story line. Most probably next year my story will have evolved and perhaps I will read this text, and say to myself, “so that’s what it was like at that time.” Because of you, representatives of society, I want to represent myself as someone “intelligible within our relationships” because that is “what holds civilization together” (Gergen, 2009: 140).

The following account constitutes the analysis of my internal voices linked to my role of mother. The text in italics represents excerpts selected from my story in Appendix A, which is told in chronological order. I have described my understanding of multiple voices in Chapter Two under Identity, and the methodology I have used to work with my multiple voices in Chapter Three, Methodology, under Point 3.8.3.

6.1.1. My “I don’t know about this” voice and “maternal instinct”

In a letter to my parents dated November 10, 1984, when I was 36 weeks pregnant, I wrote, *“I feel so unprepared, but the mid-wife says that nothing will prepare us for it anyway. John is worried and thinks I’m very courageous – not much option is there???”*

On February 16th, 1985, I wrote to my parents, *“We saw the paediatrician on Tuesday. We have another 4 weeks together, instead of one. She’s given me an*

extra 3 weeks off to get my little boy into a rhythm and to breastfeed a little longer. Don't know if that is possible because the gyni's (gynecologist's) medicine (Parlodel given 8 weeks after Edward's birth to stop lactation) was pretty radical. Apparently one should never stop so quickly. Dr. B. is a bit of a bugger not to have advised me better. Too bad, it's done!"

There are a number of stories and accompanying discourses that we could draw on from the first chapter of the story. I chose these two excerpts because they highlight how little I knew about the experience of being pregnant and breastfeeding, two bodily experiences that were hitherto unknown to me. If I were to give a name to this voice, would it be "The failed maternal instinct" or "Haven't got a clue about what is happening to me?" or "Doing what the doctor told me to do?" I am positioned by my husband as being "courageous" as if to say, "no rational human being would undertake this willingly." And then I was caught between two medical discourses by my gynaecologist and paediatrician respectively. Before giving birth I attended a course given by midwives. They showed us films on giving birth and breastfeeding. I had not seen another woman give birth. I had not seen another woman breastfeed. I was lucky that I had the book, *Our bodies, our selves* (The Boston Women's Health Book Collective, 1976), but I do not remember engaging in discussions with other women or mothers on the subject. I knew that my mother had given birth to us lying on her side, and that I would be lying on my back. Many years later when my friend, Houria, gave birth to her first child and I went to visit her in the maternity ward, she said to me angrily, "you never told me it was such a fucking disaster." There was an understanding that we didn't tell other first-time pregnant women what it was like for us. We hid the details. I am talking about the reluctance of talking about such things. We covered up with stories of how fulfilled we were, how the pain was momentary and how the midwives taught us how to breastfeed. We didn't say that we didn't really know what was happening, that we put our bodies into the experienced hands of doctors and that we were not in control of the situation. Our bodies were returned to us after the event, sometimes along with the baby washed and wrapped up in clean clothes. So we may have suffered from not knowing, but we maintained the discourse. I remember my Aunt Elsa telling us that she had got married at the beginning of the twentieth century and she didn't know anything about "how babies were made," which I take to imply that she knew nothing of sexual intercourse, reproduction and giving birth. Her voice was different to mine; it had a sound of horror to it.

To some extent I think this begs the question, "aren't we women supposed to know what to do naturally when we give birth?"

It is a biological fact that it is only women who can give birth. However the meaning of giving birth has been socially constructed in ways that often position mothers as being "single-storied". (Adiche, 2009). Adiche tells us, that reducing a person to one explanation, one story, is to diminish the potential available to that person. In this vein, Blaffer Hrdy (1999), a sociobiologist,

tells us how men of science have had an interest in positioning mothers as being totally at the service of their children. She writes, "It was no accident that first moralists and then Victorian evolutionists looked to nature to justify assigning to female animals the same qualities that patriarchal cultures have almost always prescribed to "good" mothers (nurturing and passive). Women were assumed to be "naturally" what patriarchal cultures would socialize them to be: modest, compliant, noncompetitive and sexually reserved" (Blaffer Hrdy, 1999:xvii).

Blaffer Hrdy (1999) writes how science has long been a masculine domain, a domain in which the male scientist has used science to create and maintain theories that subordinate the female to the male. Her aim of 'setting the record straight' show that studies of animals do not always function in the ways that men have described, and true to her position as a sociobiologist, she insists that it is worthwhile to study animals because, "we are studying our past, studying how human beings have evolved over millions of years to become what they are today." This seems to be a rather deterministic and limiting position, but her book does give delightful glimpses at the ingenuity and variety of animal practices of sexuality, child bearing and rearing.

Blaffer Hrdy claims there is no biological basis to maternal instinct. She writes, "If only women started to scratch furiously in the dirt just prior to giving birth! Or if after giving birth women felt an irresistible compulsion to lick the newborn all over its body, or eat the placenta like other apes do. ... If only mothers engaged in such "fixed action patterns", their stereotyped responses would put to rest the debate over whether or not there is an innate component to maternal behavior in humans. But we don't" (1999: 167).

Badinter (1981) describes how a majority of mothers in Parisian society, as recounted through official documents starting from the period of 1780, sent their new-born infants to live with wet-nurses from birth until about the age of four years old. Her historical analysis concludes that this relatively common practice is proof that 'maternal instinct' is a social construction. Blaffer Hrdy writes about Badinter, "Badinter's reasoning was simple. If mother love is instinctive, all normal mothers should be loving. If not spontaneous and automatic, maternal love had to be a non-biological social construction" (Blaffer Hrdy, 1999: 309).

Badinter relates how the subject of motherhood became not only popular, but created a discourse of maternal responsibility for giving birth and sustaining the health of children. A confluence of ideas within the context, such as the support of by politicians whose interest lay in increasing the birth rate, resulted in women being exhorted to stop the use of wet-nurses and to become nurturing mothers.

If there is no maternal instinct, is there an explanation for the attachment we feel for our children?

6.1.2. My “I’m in love with my baby” voice

I wrote to my parents on February 3, 1985, *“I find it strange to be loved (so much) for apparently doing nothing. I haven’t earned this love, apart from carrying him 9 months. I hand him around and let everyone hold him. He seems happy to be with others and he loves to look at people. When I come around, his eyes fix on me and his mouth starts working.”* At other times, I called him nicknames and I boasted about him. It was clear I fell in love with my newborn son. Today a voice reminds me that carrying a child for nine months was not something to discard so easily. I remember thanking my mother for having carried me after I become pregnant with Edward. It did not occur to me beforehand that the mother’s body is in service in such an encompassing manner. In Edward’s book I wrote about the first day at the crèche for him and the first day back at work for me, *“I was so amazed that I wasn’t with you during the day. I went from the Creche to the hotel and the first person I saw was Mr. Reber, the concierge, who asked me what I was doing, where was my baby. So I told him that I was coming back to work and that you were with Sylvaine. He told me off for leaving you. (Easy for him to say, but not easy for me to hear.). Then I went up to the office and it hit me that we weren’t together and I started to cry.”*

This voice sounds amazed by motherhood. There is almost a spiritual element to it, far from the biological practicalities. Not only was I amazed at the changes in my body, but here was this perfect little boy who loved me.

Blaffer Hrdy says that there are biological changes that happen to a woman as she becomes a mother, which are not just metaphorical explanations (1999: 94). Biology assists us in adapting to motherhood, she says. “Human mothers learn to recognize their own babies in the days right after birth, and gradually ‘fall in love.’ Since babies return the favor, the baby’s attachment to the mother further reinforces her commitment.” Falling in love is assisted through the production of the peptide hormone oxytocin, which is stimulated when giving birth and breast-feeding in the mother, but passes to the child, “circulating peace and bonding hormones ... transmitted in my milk to her, acting as a mild sedative, leaving us both with the impression that being near each other was deeply satisfying” (ibid: 137). Prolactin, a protein or lactation-promoting hormone, is present in higher levels when mother lactate. It is also present in fathers and others when they engage in nurturing behaviours.

Am I not fortunate that I fell in love with Edward, and that he returned the favour? This is a discourse that Blaffer Hrdy helps me to construct, for which I am grateful. Now comes the sticky question that is so often asked of mothers, but not of fathers, is “Why did you leave him, if you loved him so much, in the crèche for others to look after him?” My question reflects the discourse that “Mother is still ultimately responsible for the custodial care of children” even when she is working full-time (Genevie & Margolies, 1987: xxv). However there is another part of it which questions me about, “why are you not fulfilled

with the role of the stay-at-home mother? Why do you want to go back to work?"

6.1.3. My "I don't want to be a stay-at-home mother" voice

I wrote to my parents on February 3, 1985, about taking part in a discussion group at the Catholic parish with Father Richard. We had read "*Laborem Exercens*" (Of Human Work) written by Pope John-Paul II. Here is an excerpt from the letter. *"He [John-Paul] may be a wonderful man, but his views on women are influenced more by Paul than Jesus. Motherhood is Woman's Role (hard to imagine fathers giving birth), but in spite of me being over the moon at being a mother, I feel he has yet to realize that 1) it's not the only one for a woman and 2) he excludes all thought that men might be happy to take on more "woman" tasks if society allowed them. I can't imagine that the world will continue as it is now – economically and society structured in this so dividing manner (woman vs man role) and what bugged me in Laborem Exercens was that the Pope seemed to be as "with it" as Ronald Reagan⁷ exulting in yesterday's values. I think we'll end up with Latin masses. Richard smiles at me when I go on about feminism but assures me I am right to voice my opinion on such issues."*

In summary, I can give all this now well-rehearsed reasons for not wanting to be a stay-at-home mother:

- I didn't like the isolation of being a stay-at-home mother. I did not have a circle of friends in Geneva because I had moved there to work in 1980. I didn't want to stay at home, stuck in the constraints of the four walls of our apartment. Even if I could be busy all day, I was lonely.
- I didn't particularly aspire to the role of housewife and home-maker. I was never particularly inclined to do needlework or cooking. I didn't see myself as having to provide a welcoming home for my husband at the end of his working day.
- We didn't have sufficient income from one salary. My husband's salary was higher than my salary although I had a higher position in the same hotel. I enjoyed having my own income or contributing to the family upkeep.
- I enjoyed my work as training manager. I was always on the move. I was constantly working or talking with others. I saw the purpose of my role in the hotel and was recognized for undertaking my role well.

⁷ Susan Faludi's book *Backlash* (1992: 62) describes Reagan's men during this period of time who "proclaimed, 'American mothers who work and send their children to faceless centres rather than stay at home to take care of them are weakening the moral fiber of the Nation.'"

- We had the possibility, thanks to our friends in the hotel, of having a place in a crèche for Edward, which was just next door to the hotel.

Why do I have to give reasons for wanting to go back to work? Why do I, as a woman, have to justify my preference to go back to work? Why don't we ask fathers why they don't stay at home and look after the children? I have seen a Swiss senior manager's curriculum vitae where he listed "family" under his hobbies. I wondered what the reaction would be towards women if they labelled being a mother as one of their hobbies.

I am giving you my reasons because I want you to know that I do not feel that I was a "bad mother" for having gone back to work. I sometimes stress the impossibility of being able to live on one salary, and argue that mothers who have to work for financial reasons have an easier choice. This voice values equality between men and women, and does not take kindly to others deciding what is right for her.

6.1.4. My "It's ok to leave my son with someone else" voice

I wrote in Edward's book, *"When you were ten weeks old, I went back to work and I took you to the Creche Carfagni in the Paquis area. There were two girls, Sylvaine and Maria, who looked after you. You had your own bed with the toy Charlotte had sent you across the top. Sylvaine put on a funny high-pitched voice to talk to you and it made you smile and laugh. Sometimes I would imitate her and you would smile for me. She would say, "Qui fait des jolies risettes⁸?"*

Blafer Hrdy argues that even if only mothers lactate, it is not only mothers who can nurture, and presents the case for "alloparents," people in the community who can take care of children in the place of the mother (Blaffer Hrdy, 1999: 91). However she does strongly put the case for newborns' and infants' needs that cannot be argued away by attachment critics who, she says, assist professional mothers today in "persuading themselves that infant needs are negotiable as an employment contract" (ibid: 491). She stands up for Bowlby's "central premise of his model: infants seek secure attachments and need a secure base for healthy emotional development" (ibid: 495).

There is ample literature today that shows that a child's "secure base" does not have to come purely from the mother's continuous presence. In psychology textbooks, such as Schaffer (1996) and Smith, et al (2003), there are many researches that recognise, for example, "early attachments are usually multiple, and although the strongest attachment is often to the mother, this need not always be so" (Smith, et al, 2003: 94). They write, "In a survey of data on 1986 non-industrial societies, it was found that the mother was rated as the 'almost exclusive' caregiver in infancy in only five of them. Other persons had

⁸ Who makes such a pretty smile?

important care giving roles in 40 per cent of societies during the infancy period, and in 80 per cent of societies during early childhood (Weisner and Gaillimore, 1997)” (ibid: 94). Schaffer (1996: 136-7) writes of the research done with the Efe community in Zaire, where “the average number of caretakers for the group of infants as a whole was 14.2, with a range from 5 to 24. From the second year on the infant has a more focalized relationship with the mother, but it remains in the context of relationships with other familiar and willingly available individuals.” In a summary of factors or criteria (ibid: 137), Schaffer tells us children can build secure attachments with adoptive parents, day care staff, metapelet (the professional caretaker employed in Israeli kibbutzim to rear children), fathers, through irregular and minimum interactions, and not necessarily through providing food or physical care. Schaffer says, “what does appear to matter [...] is the quality of the interaction. The provision of fun and playful stimulation is one such qualitative aspect [...] another aspect is the sensitive responsiveness of the adult in relating to the child” (ibid: 137).

I have chosen to draw these examples from these two social or developmental psychology text books from my master studies in psychology to show that there are studies, or academic discourses, that can be used to help mothers in making their choices about available child care. I would like to be reassuring and say, “if it’s available and good, your child will not suffer.” Using the discourse in this manner is buying into the discourse because it could be useful for me to do so. Reading Singer (1992 in Woodhead et al, 1998) pulls me back into a social constructionist point of view that asks me whether I am ignoring what all researchers are potentially doing, i.e. playing power games. She writes in a chapter entitled *Shared care for children* from a social constructionist perspective, “My theoretical starting-point is to recognize that ‘the child’ whom the psychologists study is a social invention: ‘the child’ is a nexus of power relations, policy concerns and value investments. Very often we are scarcely aware of just how deeply our theories, concepts and research questions are anchored in moral and social-political choices and problems” (ibid: 65).

6.1.5. My “I am a dutiful wife” voice

In a letter dated November 26, 1984, I wrote to my parents, “*The latest crisis is John’s in plaster with a strained Achilles tendon from running. So I’m driving myself and him to hospital and getting a double room. He went running on Friday and after 12 kms it started hurting. Luckily he was almost home and I took him to the doctor’s straight away. I take him back to the hospital on Thursday for a further check. It hasn’t “gone” completely so there’s a good chance that it will heal quickly, but no races for a while.*

In a letter to my parents dated April 7, 1986, I wrote: “*What does a housewife do on her first day at home with hubby out at work? Does Monday have to be washing day? John has got the job he wanted – F&B Manager at Ecole des Roches hotel school in Bluche. ... So we are now permanently (!) installed and*

John's salary will amply cover one non-working wife, 2 kids and paying back debts. Hooray – I'm very proud of my man."

One of the things that struck me when writing was my story was the way I talked about my husband to my parents in my letters. I was terribly concerned about his well-being. I name this voice "the dutiful wife." This voice seems to resemble my mother's voice. When writing to my parents about Edward's christening, I write of all the things I did on the day, and state proudly, "I am my mother's daughter."

And here we come to a site of conflicting discourses. You have already met the voice that denounced John-Paul II for his views and stated that she was a feminist with the right to go out to work. And here is a voice that accepts and whole-heartedly takes care of her husband, puts his needs first and congratulates him on being the main bread winner. The historical background of this traditional role, and its effects, have been described by many feminist writers, such as de Beauvoir (1949/1953), Friedan (1963), Greer (1970, 1984), Millett (1969/2000), and Rich (1976). Badinter (1981) sums it up for me, when she states that although women were responsible for their children, they were primarily responsible for their husband's well-being. When mothers handed their children over to wet-nurses, they were ensuring that their husbands came first.

Fraser's (2008) *In the name of love: Women's narratives of love and abuse* tells me that "love" is like "motherhood," an abstract concept that encompasses practices and discourses, and should be studied because of its importance in our lives. She writes, "It is so meaningful that it constitutes part of the Western definition of what it means to be human. Imbued with desire and socially regulated but individually expressed, love involves a complex web of emotions, motivations, actions, and explanations. Research can help us to make sense of these complexities, particularly if it helps us to understand more about the ways power infiltrates the intimate spaces of everyday life" (Fraser, 2008: 18). My voice is perhaps one of love, but it also includes notions of compliance and deference as if my husband had more rights than I did. I maintained the discourse and his sense of entitlement. Harré et al (2009) would say the position of the dutiful wife has rights and duties. Put simply, a dutiful wife has the right to being taken care of financially in return for taking care of her husband and children.

6.1.6. My "protective mother or the wolf-mother" voice

We often use references to animals to describe our way of being as mothers. Hen-pecked husbands and children are supposedly forever being heckled by the mother hen. It is not a term that I like, nor do I appreciate the behaviours of the mother that it describes. However, there are times when I have gone on and on at my children that they most probably remember better than I do. The Chinese tiger mother has recently been described by Chua (2011) and in disparaging

terms in the press as a result. Wolf-mother seems to be a more appropriate term. It means to me that I am a mother who nurtures when need be, who defends her children when need be, but who also pushes her children out to face the world. The following extract from a letter to my parents on February 26th, 1987, seems to describe a potential beginning of the voice of Edward's mother. *"We have had another heart-breaking stay in hospital with Beatrix. She went in last Tuesday and had her hernia operated on on Wednesday morning. I visited her on Wednesday lunchtime and she was functioning well. On Thursday she was fine and the doctor said I could take her on Friday. So I went down on Friday and the nurse said to change her before leaving. I nearly fainted when I saw the scar. Then I could have killed somebody, like the doctor, but nobody was around at lunchtime. The nurses had to take over dressing her and assured me that it will clear up and there will be no scar left. It is about six centimeters long. On Sunday I got a friend who is a pediatric nurse to have a look at it, and she said it wasn't healing properly. So I nearly fainted again. Then I called up the doctor on duty at the hospital and all he could find to say was 'well, it was very big.'"*

In this situation I am dealing with a voice of mine that is well known to me. It is my "squeamish" voice, the one that hates to think that we have blood and guts inside us. This is the voice that goes to the doctor and wants him or her to take care of my body and give it back to me, like the gynecologist-obstetrician did. It is the one that explained how I felt when I went for my hysterological examination in January 1984. And competing with this voice is another one that could have killed the doctor for his appalling handiwork. I have a memory of an appointment with the pediatrician who said how difficult it was to stitch the stomach walls, and asking him if he would like to see my caesarean scar. I remember standing up ready to pull down my trousers. I asked him, what am I going to tell my daughter when she asks me, "why did you let them do this to me?" He told me my daughter could have cosmetic surgery later on. I was horrified.

6.1.7. My "bewildered mother or the take-charge mother" voices

Edward started school in September 1989. He was not quite five years old. He went to a private school where Beatrix, his three-yearold sister, could attend playschool. By April 1990, we decided to take them out of the school and I wrote to my family, *"Edward is doing badly at school with his hysterical Rumanian teacher. He really has had a hard time so after Easter he will change schools and go to the local school."*

This voice goes from being bewildered about what was going on, and wanting to take charge and sort it out. I thought that it was the teacher that made the difference. I had been influenced by John Holt's books *How children fail* (1964/1983) and *How children learn* (1967/1983). His first book about children failing is based on his daily personal accounts of how he was interacting with the children in the classroom. Holt describes, in his foreword to the revised

edition (1964/1983: 5), his values and beliefs that it is the teachers' responsibility in finding solutions to help children learn. So I moved Edward to another school, and later on I found myself being told off for not doing Edward's homework with him. This was to be a constant reproach. My friend, Eva, told her daughter, Lea, when Lea was in first grade that she, Eva, had passed first grade and that she did not have to do it again. She told Lea that it was up to her, Lea, to do her homework and if she couldn't do it then to talk to the teacher about it. I had not expressed myself perhaps so eloquently, but this story remained because it was meaningful to me. However when I was studying psychology, my studies informed me that children learn many things with their parents before they go to school. As I re-read the foreword to Holt's book on how children learn, I read, "It is before they get to school that children are likely to do their best learning." I often think how useful it would have been for the teacher to remind me of all the things that Edward had learned with me, and how the caring relationship between parent and child can be helpful for the child to learn. That idea fuels my "guilty voice," one that you have met already and holds me responsible for not having done enough.

Malacrida (2003: 253-4) writes about how her daughter's teacher proposed that she were "taken off homework detail." She writes, "It was a simple plan, and one that we all worked on together. Hilary either did her homework, or she stayed after school to catch up. And if she stayed after school, we were to devise some kind of 'consequence' to compensate for the fact that we had to pick her up rather than have her come home on the bus. The teacher facilitated these arrangements. *Facilitated* them" (her italics). May we all applaud that teacher.

According to Swiss law, I am responsible for the education of my children and I don't know exactly what that entails beyond being obliged to send my children to school. We now have 11 years of obligatory schooling in Switzerland. The first two years of optional schooling, or what was called infant school, has now become obligatory. Children are obliged to attend school until the age of 15 by which time they should have completed the three years of "le cycle d'orientation" (or "middle school"). I might be held responsible but I am also obliged to send them. There is no choice in the matter. I often have the feeling that we are close to what Goffman calls a "total institution" (Charon, 1992). Donaldson (1978: 13) writes, "When we make laws which compel our children to go to school we assume collectively an awesome responsibility. For a period of some ten years, the children are conscripts." I am not alone in my comparison.

In one of the most widely distributed weekly Swiss magazines, the Migros Magazine, there was an interview published with Isabelle Chassot, the head of the federal cantonal directors of public instruction (educational department) in Switzerland. She is quoted as saying, "The parents are primarily responsible for the education of their children. It is the law on education that reminds us of this reality. It consists of a difficult mission based on making educational choices

for which they are responsible, but also on ensuring that the children are brought up within “love” [She does not say “within a loving, caring environment.” She uses the abstract concept of “love”.] Happy children are better equipped to learn, to integrate in a group and to increase their autonomy. The task of the parents is to help the school to turn the child into a responsible person, capable of realizing himself in his adult life” (*Happy children learn better*, Migros Magazine, 2010, 34:30, translated by me). This does not sound like an invitation to collective responsibility. It sounds like an expectation made of parents to partake in an abstract practice. As McNamee (in press) would say, it is the norms and expectations that imply values and beliefs that underpin the coordinations between the teachers and the parents. By stating that children are happy because of the way they are raised by the parents, is to ignore what was written by Donaldson and a multitude of other researchers that what happens in the classroom also counts. During my studies in developmental psychology, I was excited by Wood’s (Wood, 1986, in Woodhead et al., 1998: 171) work on how children learn at home with parents who attend to what the child is interested in, and that teachers have to involve children to gain their attention which they unfortunately do by controlling through questioning. He writes, “Teachers often know the answers to the questions they ask, and children, by four years of age, possess the ability to recognize this fact, in some contexts at least” (Wood and Cooper, 1980). I give this as an example because of my interest in the way teachers talk, following the research with Evison (1990a) looking at how trainers talk to adult participants in technical training. I sometimes wonder whether Piaget did more harm than good for the Geneva school system, and if we would not have been better off with a Vygotskian approach of assisted learning. Edward was a happy, little fellow before he went to school. Within a couple of months and bewildered by the explanations and implicit expectations of the teacher “to do something”, the take-charge mother took him out of that school, and put him into another in the hope he would be happier and learn better. Donaldson’s stance includes the teachers and the system in her invitation to investigate. She writes, “There is no denying that, in spite of the enlightened concern of our primary schools with happiness, schooling somehow or other turns into a distinctly unhappy experience for many of our children. From it large numbers of them emerge ill-equipped for life in our society and inescapably aware of it” (Donaldson, 1978: 14). She goes on to say that we need not position ourselves defensively, either as student or teacher or parent, because “[d]efensive postures are usually the enemies of effective action” (ibid: 15) and that we need to recognize the “extreme difficulty – and in the context of human evolution the extreme novelty – of the educational enterprise which modern Western cultures have taken upon themselves.” Any solution, she writes, “consists in discovering how to transform an existing state of affairs into a desired one that has not yet come into being” (ibid: 15).

Today I have little opportunity to use my “take-charge voice” or my “bewildered by teachers voice.” To use Harré *et al.*’s simplified positioning

theory (2009), I wonder whether parents really understand what is expected of them by the teachers in terms of rights and duties. Listening to the younger mothers I interviewed talk of their experience, I can see how they manage the relationships with teachers. They have found themselves ways or strategies of negotiating with teachers that sound more like bargaining. I have yet to talk to teachers.

6.1.8. My “I’m frustrated” voice

From a letter to my friend, Stefana, dated August 6, 1990 after three weeks vacation with the children.

You know, I mean, you may not know that having children is not what it’s made out to be? Do you? It may have been the “done thing”, but it makes you wonder why you did it? Or do you dream of spending your holidays running a 24-hour child-care service, doing everything you don’t really want to do, but because you are one of those strange people called a MOTHER you don’t dare own up to not wanting to???? [...] Oh, Stef, I do long for the days when we hung out, smoked cigarettes, talked about all kinds of things, drank a little wine, danced at the Darling, and got up in the morning when we felt like it.

This voice sits uncomfortably with me. I wonder whether I wrote to my friend, Stefana, in this way because she didn’t have children. Would I have owned up to being fed-up and frustrated with another mother? Now I wonder what my outburst did to my friend who didn’t have children. Women who are not mothers have told me of the weight of expectations that they should have a child. Part of me thinks that I wrote to Stefana also because I wanted to reassure her that motherhood was not everything that it was made out to be. Was I being responsive and, if so, was I being helpful or tactless?

There is also a moment, more than a moment of worry, about including this text. Will my children read it and deduct that I was not an “essentially good mother?” Will they worry that they deprived me of living another life, or that I had to make undue sacrifices in order to raise them? Do you too experience discomfort when you read some of the feminist writings of women who write of being angry with their children? Such as Hopkins (2005b) who relates another woman’s experience by quoting her writing, “*As described so exquisitely by Adrienne Rich (1979) I experienced both deep joy and indescribable agony as I tried to fulfil my mothering destiny. At every step I fell short of the ‘ideal mother’ that existed inside my head. Guilt became the mother of my existence. My sense of isolation, both from myself, and the experience I came to view as the real life that lay somewhere out there in the real world, created a spiral of confusion and anger. Depression became a constant companion and tears flowed endlessly. In 1986 I left my marriage. I left my children with my husband. Simone was 6 and Celeste was only 2. As I remember it, my reasoning went something like this ... I have to have freedom or I will die ... I am a bad person and a failed mother*” (Hopkins, 2005b :7-8, original italics).

When I read how this woman, Sandy, left her children with her husband to find her freedom, I shudder. Would I have ever got to that point? Was I really fed-up of my children? I know that I have continued to have a voice of frustration, one that says, "Please let me be. Clean up after yourself. I don't want to have to do this for you any longer. You are grown up." When reading Northrup (2006) I found a medical doctor saying that when women are peri-menopausal it is not their hormones that make them emotional (read angry), but that the years of self-sacrificing that catches up with them and they finally admit to no longer wanting to be the family slave. Genevie & Margolies (1987:35) write that even the most contented of mothers "experience stress," and they too quote Rich, "As author Adrienne Rich notes, 'the physical and psychic weight on the woman with children is by far the heaviest of social burdens.' Even when a mother does take a positive approach and does not feel chronically overburdened by motherhood, the responsibilities lead even the best, most unconflicted mothers, to crack under the strain from time to time."

When I was interviewed for a position of learning and development specialist in 1987, I had not been working continuously outside the home for over a year. The hiring manager said to me, something along the lines of, "I hope you realize that working full-time is not as easy as staying at home and looking after children." So I asked him in return, "Have you ever spent a day at home with two children under the age of two?" He replied that he hadn't. Staying at home with two children under the age of two, looking after them and running a household, can be extremely demanding, I told him. The idea of coming to work every day and leaving the muddle behind seemed as enticing as going on vacation. And my experience bore my opinion out. In my line of work – training and development of employees in a large American multinational – being in the office implies that you can plan what you have to do, allocate time to doing those activities, and not be constantly watching out for a child while doing other tasks, interrupted constantly. There are many jobs that require the flexibility required of a housewife-mother such as working at customer service in a supermarket or a nursing aide in a hospital, but even then you can go home after your shift is finished. I remember driving home one evening from work, thinking that it would be great if I could stop in a bar and have a drink before getting back. Instead I would keep my lunchtime breaks for a sole activity such as going for a walk, or window-shopping downtown, or lunching with a friend.

There is another dominant cultural discourse about custody of children after divorce. Blakely (in O'Reilly, 2001: 27) elates that her editor called her an "unnatural mother" for allowing her thirteen year old son to go to live with his father. She writes, "'I can't understand any woman who would voluntarily give up custody of her children,' the editor told her staff, calling my behaviour 'appalling'." In Switzerland, I was told that there was a small percentage of mothers who were not given custody of their children after divorce. They were

the criminals, drug addicts and prostitutes. Being subject to that discourse, wouldn't every woman want to be given full custody of their children?

6.1.9. My "Am I really to blame" voice?

Extract from my personal journal on October 6, 1991: *There is so much going on that I need to separate things so I can think straight. Edward: There is a point that in my mind does not make sense. If John was brought up so beautifully, so stable and balanced, why does Edward trigger such anger in him? Why does he say things like, "I'll send you away" [to Edward] and "If Edward is having problems it's because you're not being a proper mother [to me]."*

I may have been bewildered by what was going on at school, not understanding why Edward was not fitting in at school, but here was a confused voice. I didn't understand why I was to blame for Edward not doing well. I started writing my personal journals in May 1991. Among my first lines in that first note book was the following one: *I have finally bought my notebook to record my thoughts, my achievements, to help clear the confusion and bring clarity, shining bright, to my darkness.* I don't know if my writing in those days helped to clear the confusion. It has served the purpose of recording what was going on. It must have been helpful in some way because I don't think I would have otherwise continued.

By this time we had heard from a child psychiatrist that if Edward had problems it was because of our marital conflict, and we were in couple therapy. Our couple therapy seemed to reinforce the understanding of my responsibility for organizing the household, which included coordinating with the aupair girls, and taking care of the children outside my working hours. I had learned a meditation technique, sophrology, so that I could take ten minute breaks to relax and find my energy. It was recommended by our family physician, the only professional who seemed to acknowledge my "double shift" as he called it. Being blamed for Edward's problems made things worse rather than better, I found myself in a Catch-22 situation. I could only stop working and look after Edward full-time if John gave up his studies and went back to work. My duty to my husband seemed to take priority. I continued working and being confused, and my "guilty voice" started taking a hold.

Badinter writes how the literature in the 18th and 19th century about motherhood changed from holding mothers responsible for the physical well-being to include the moral well-being of a child. She writes, "Women of good will enthusiastically seized upon these new responsibilities, as evidenced by the prodigious number of books on raising children written by women. There was a new awareness that the mother's function went beyond the biological to the moral: it was her duty to raise a good Christian and a good citizen, a person who would benefit himself and society. What was new was that the mother was

now considered the person in the best possible position to take on these tasks (Badinter, 1981: 205).

In the twentieth century, Badinter writes that mothers became “accountable for her child’s unconscious mind and the fulfillment of his desires” through Freud’s psychoanalytic theory. Freud had used the same technique as Rousseau(1762), and created the role of the “model mother.” This model mother was synonymous with “feminine nature” and “normality” (Badinter, 1981: 206). From this point in time, women became entrapped into living up to the expectations established by these standards for fear of appearing abnormal, and the weight of responsibility upon mothers grew. She writes, “From responsibility to guilt there is only one step, quickly passed over when the child has the slightest problem. Henceforth, it would be the mother who would be called to account for any and all deviations from the ideal. (ibid: 206)

Blakely (in O’Reilly, 2001: 38) writes, “I wish it were true that a mother was the most powerful influence on her children, but her singular power is for a limited time only, in early childhood [...] However diligent she may be, however dedicated, no mother can escape the larger influences of culture, biology, and fate. Culture shapes the human mind with television, books, films, friends, teachers, coaches; biology governs the body with genetic codes, some imprinted with preset timers for schizophrenia or juvenile diabetes; fate can change a young life completely, with a motorcycle accident, a bullet, a broken neck. Even within the remaining quarter’s worth of family influence, a mother shares her fraction of power with fathers and siblings [...] Until mothers become the sayers and the makers of the culture, until we can actually live in a culture where mothers and children genuinely matter, ours is an essentially powerless responsibility. Mothers carry out most of the work orders, but most of the rules governing our lives are shaped by outside influences.”

6.1.10. My “I’m angry with my husband” voice

An excerpt from my personal journal dated December 31, 1991: *I looked at the accounts in the morning and I calculated how I could cope if I didn’t have him around, and I could cope without asking for child care even! I could even pay the mortgage on my own!!!! [...] I am tired of this anger.*

Many, many years ago I subscribed to a German magazine *Freundin* (Girlfriend) and there was an article about “women having it all,” which said that a working mother had to deal with five things. One, her job. Two, her husband. Three, her child or children. Four, her home. Five, her social life: family, friends, hobbies, etc. It said something along the lines that a woman could manage four, not five. If I remember rightly, their argument was that if the percentage of women requesting a divorce was increasing, then it was because women were deciding that if something had to give, and often it was the relationship with their husbands. John and I separated in January 1992. This angry voice continued to keep its grip on me. It was no longer fuelled by daily

contact, but John's "sense of entitlement" also kept its grip on him, and he continued to hold me responsible for raising his children, which fuelled this voice. Writing my story and reflecting critically on the events, with the help of social constructionist and feminist authors, allowed me to find other explanations beyond the personal.

One of Sampson's (2008) explanations is that some of us, including woman and African-American, have been positioned as "other". He says, "The other is a figure constructed to be serviceable to the historically dominant white male group. In order to provide this service, the other cannot be permitted to have a voice, a position, a being of its own, but must remain mute or speak only in the ways permitted by the dominant discourse" (ibid: 13). This positioning develops a "sense of entitlement" of those whose interests are best served by dominant cultural discourses, and until the discourses are deconstructed, they are almost invisible.

Blakely (in O'Reilly, 2001:26) writes, "'Dominance makes a ruling group stupid,' the late columnist Sidney Harris once wrote about the privilege that's bestowed at birth upon certain white, heterosexual men." To find someone who wrote about the men's perspective, I came across Robert Bly's (1991) *Long John: A story of men*, and found a story about how men have to fight their mothers in order to re-gain their masculinity. I didn't find it particularly helpful and gave it to my partner, Jean-Luc. I read the introduction to Anthony Astrachan's (1986) book *How men feel*. He writes, "The women's revolution is challenging men's hold on power and reshaping men's roles in society. But few people have examined the way men respond to this revolution, in real life [...] we take it for granted that some men welcome it, while more feel threatened by it and resist it. [...] I wanted to understand why. Why do we have so much difficulty treating women as equals in work and in love, why do we waste so much of their energy and talent and feeling and so much of our own, why do we inflict so much pain on them and on ourselves? [...] The answers, I discovered, had to do with male power and male powerlessness and the way we see the power of mother in women's challenge to both" (ibid: 3). As much as I am pleased that there are researchers who delve into this subject, I wonder how many men read this work, and how many men read feminist research and stories written by women about their experience. I fulfil the stereotype of attentive women who feel they are responsible for their relationships with men by reading about men. My aunt once gave my uncle a book on men and women and their relationships. Afterwards he told her, when she asked if she had read it, that he had read the interesting bits and skipped the uninteresting bits. On further curious probing, she found out that the interesting bits were about the men and the uninteresting bits were about women. He too upholds the stereotypical image of men.

The other part of Astrachan's introduction that I find personally difficult is to read about the "power of mother" as one of the challenges to male power and powerlessness. Have I become so suspicious that I react immediately thinking,

“oh, no, more blame to come!” However I have omitted one of his questions and I present it now. He writes, “I wanted also to understand why we achieve such joy when we succeed in creating a dynamic of equality with women, and how some of us do it.” Being a fervent facilitator of groups in organizations using Appreciative Inquiry, this appeals to me.

Reading Jenkins (2009) also gave my “angry” voice some hope about men dealing with men’s dominant ideas and practices, that can sometimes and unfortunately lead to abuse. Jenkins (2009: 129) writes that men find themselves “in a context of dominant cultural interests which are reflected in ideas such as :

A father should always be in control of children.

A father should always be right or always have the last word.

You must maintain discipline, even if the child fears you.

A child should do as I say (regardless of what I do).

Breaches of rules must always be punished.

You can’t walk away from a confrontation.

Any lapse should be regarded as a sign of weakness.

Children should always respect (obey and defer to) their father.

If they fear you, they will respect you.

Any lapse should be regarded as a personal slight or rejection.

Fathers are responsible for discipline (punishment).

Mothers are responsible for nurture.”

Jenkins (2009: 126) points out, “The man is not responsible for these interests or the political structures and processes which constitute them. However, he can take responsibility for his participation in practices which they prescribe; he can develop a political understanding and mobilise his capacity for resistance. These political preoccupations stand in stark contrast to notions of causality.” Jenkins talks of “sets of dangerous ideas” that “inform abusive practices, and that “the *externalisation* of dangerous ideas” makes them “and their history visible and accessible to challenge and resistance (White, 2008, *italics original*).”

Working with White’s (2007), Jenkins’ (2009) and Winslade and Monk’s (2000, 2008) narrative practices seems to be so different to what I experienced in couple therapy. My experience seemed to help my anger develop, as it did with the medical dominant discourses.

If I take an externalisation perspective on my anger, rather than using Voice Dialogue to discover where my anger comes from and what it has to say, I can look at what my anger has made possible. It did invite me to become aware of choices that I had not considered before. It stood by me when the voice of

Catholicism reminded me that I had made a vow to stay together “through sickness and health, til death do us part.” I was always helped by a Catholic priest who told me that his job was to look after the survivors, and that I was likely to fall ill if I didn’t step out of my marriage. He repeated many years later to a woman, that I made the choice for my children, not for myself. Anger kept reminding me that I had made the better choice.

The narrative practice of externalisation also allows me to see myself as not an essentialist angry woman. I am not “totalized” (White, 2007: 37) by the problem of “anger.” It drives me to take action, but it also fatigues me. White writes, “A sole focus on fight metaphors has hazards [...] it can contribute to an entrenched “fortress mentality” with regard to life, as well as to an increased experience of vulnerability and, over the longer term, a sense of fatigue and reduced personal agency.

6.1.11. My “grateful and hopeful mother” voice

Ms. Sylviane, Edward’s teacher wrote in his end of year report card in June 1992, *I find that Edward, in spite of everything, has made great efforts. He has become more open, receptive and perseverant towards his work.*

In his school report of November 23, 1995, his teacher, Mrs. Iovino wrote: *Little by little Edward has installed himself in his school work, of which he understands much better the rules. He willingly asks for more explanations when he is in difficulty. It is good! The next objective is that he has more confidence in himself.*

These reports made my heart sing. Mrs. Iovino, especially, gave me faith in the teaching profession. She ran a small class for children who needed more attention in a private school. She not only recognized Edward’s efforts, but she knew how to anticipate his moments of dwindling interest and find a solution to him looking for something more amusing to do, like meddling with his school colleagues’ work. She asked me to stop giving Edward Ritalin because she said she could handle him without it. She told me how to help him prepare for his dictation on Monday evenings and Edward soon saw the benefit of preparing. She helped him to enjoy school and make friends. She made me feel that it was going to be alright. In spite of Edward being labelled dyslexic, he learned to read and write with Mrs. Iovino. This voice of mine came to believe that with the right teacher Edward would make it through obligatory schooling.

6.1.12. My “I’m drowning” voice

There is a voice of mine that I do not enjoy revisiting even for the sake of this dissertation. I do not know if “drowning” is the right term. I felt that I was drowning, the situation seemed to spiral out of control. I can feel this voice take hold of me right now as I write. There is tension in my head and in my gut. I am sweating. I want to puke. I might have survived this, but the feeling lingers on. This voice of mine was regularly present in my life for the next seven years, until 2003. It involves feeling confused, helpless, and useless. It invokes crying,

feelings of anxiety and exhaustion. It made me wish that life would stop. It eventually became public, visible and elicited support.

In my journal I wrote on October 12, 1996, *“Received a letter from the Tribunal tutélaire (the guardianship court that handles questions of custody and rights of visit) yesterday. I have to ‘umstellen mein Kopf’ (turn my head around). John has a right to the children, but no obligation to take them. [...] Jean-Luc says most mothers don’t want their children to go the father and I am the opposite. I believe when one has a right, then one has a responsibility. [...] Meeting with Mrs. Steffen, the social assistant of the Service de la Protection de la Jeunesse (Youth Protection Services) on October 14.”*

I wrote in my journal on October 20, 1996: *No, John doesn’t want custody. He does have two pages of reproaches towards me (and Jean-Luc) for all kinds of things. The World has done him wrong – the judge has taken away his children, his ex-wife mistreats him – oh woe is he! Had an extra session with Evy (my therapist) to keep my head above the shit. She says he must be in a really bad state. She tells me, be strong towards them all and show that you cannot be put down by such stupid slander.”*

The social assistant told me she would take the case on to protect everyone’s interests. Later she told me that she had asked John to stop harassing me. However “protection” by a social assistant is a two-edged sword. She also turned her gaze on me and we had a monthly meeting with the children. For the next three years she would monitor the visit rights and the quarterly planning of visits and vacations. She upheld the father’s rights. She told me that I was powerless when it came to him cancelling a weekend or a vacation, even at the last minute. She was the person I turned to at the end of July 2001, and she assisted Edward in being admitted to the Crisis Unit for Adolescents. It was a strange relationship, and did not alleviate my drowning voice. It may have held it at bay at certain moments. She listened to me, but reminded me constantly that “it was a man’s world.”

Espin and Gawalek (in Brown and Ballou, 1992: 102) write about humanistic, person-centered theories and critique the “hearing and respecting a woman’s experience as a person” which they claim have “two basic premises [...] that are quite problematic for feminist psychology theory. The first is that a person’s ‘story’ is reflected and accepted as told. While this may seem validating, it may also create the opposite effect. Since all women are victims of an oppressive society, simple acceptance and reflection may result in validation of the oppressive status quo, or in defining as pathological that which is a defensive reaction to an oppressive situation (e.g., the high percentage of depression in women). The second assumption of person-centred theory is that the locus of control lies within the individual. This assumption is simply untrue for women who experience multiple discrimination: By definition, the external world is a major source of controlling factors in the lives of women.” Although I am not quite comfortable with the totalizing stance of the authos, I include to highlight

the need for an approach to help women take charge of what they can take charge of, to help them feel less disempowered.

Extract from the report made about me by Dr. R., psychiatrist at Geneva University Hospital on May 5, 2002, after I was hospitalised: *“Anamnesis elements: Female patient, English nationality, divorced, mother of a 17 year old son and a 15 year old daughter. Her son suffers from Klinefelter syndrome with frequent behavioural problems. He is in the care of the SMP (Service medico-pédagogique). His behaviour has deteriorated in the past few days. The patient is exhausted, having suicidal thoughts. She is treated by Dr. C. who has sent her to this unit.”*

The day I was hospitalised I had started to cry early in the morning. I drove Edward to see his endocrinologist, Dr. S., in the morning and said I was not coming in to the hospital because I could not stop crying. I then went to see my physician, Dr. C., who told me not to show any sign of strength and “no humour” when I went to the admissions department in the hospital. He told me that my humour allowed others to believe that I was actually coping. Asking me to be interned is a humbling experience. Breaking down is a personal act. Asking to be interned, to have somewhere to go to because you cannot cope, has to be done in public under the scrutiny and gaze of medical doctors and professionals. I was told to say that I was having suicidal thoughts because saying that I was exhausted and could not cope anymore would not allow me to be interned. It did draw attention to my situation by the professionals at the SMP who were supporting Edward.

Extract from an e-mail update to John dated June 5, 2002, following a meeting with the SMP: *“We also talked of putting Edward under “tutelle” (legal guardianship). Madame H. (the social assistant) was horrified, but it is up to the judge to decide when and if we request it. This would mean that Edward would not come of age, and the judgement is hard to reverse. She suggested that Edward could ask to be put under a “tutelle temporaire” (temporary guardianship) at the age of 18. Jean-Luc told her at this point that her recommendation was not welcome. He got very, very angry with her and told her that while she and the others sat in their ivory tower from 9 to 5, I was the one whose nerves were being played with and had to go to hospital. The SMP will not look for another place in a foyer. I do not know if they still harbour the idea that Edward could/should come back to live with me. I don't want to play the violin, but I am still very fragile. Dr. C. has prescribed Prozac to me today and told me to keep on working at 50%. Every time there is an upset, I am back to crying fits.*

A year later, this voice still has its grip on me in the situations that are daily occurrences. Entry in my personal diary on April 12th, 2003: *Loads and loads of pain and tears for Edward.*

E-mail to my family members on April 13, 2003: *I had a really rotten day yesterday, loads of tears and anger about him being locked-up and feeling very*

helpless. It sort of hit me in the face. Jean-Luc managed to keep close until it was over which was very brave of him.

Entry in personal diary dated June 18, 2003: *Yesterday I was the saddest I have ever been. We went to the guardianship court and Edward was put under guardianship, deprived of being totally responsible, and Jean-Luc was named guardian. I cried a lot.*

Excerpt from a letter to Jenny, our friend and former aupair girl, dated July 1, 2004: *It has been heart-breaking for me to see all of this happen and to feel so helpless and useless.*

6.1.13. The voice of Edward's mother

There are multiple threads that feed into this voice of mine. For a number of years, I looked for a place where I could be in relationship with Edward without too much tension. Reading my letter to Jenny I become aware of how our relationship developed following his release from the psychiatric hospital and moving into his own flat. I wrote, *"Now we see him a couple of times during the week. He comes for supper regularly. He calls me when he is sad and he cannot cope. He takes absolutely no medication. The doctors worry about him but he won't go to see them. His teeth are almost rotten but he won't go to the dentist. I call him a couple of times a week and he is happy that his Mum loves him. There is a lot of tension between him and John. I don't listen to John on the subject of Edward because I am not his waste-paper basket for his emotions. Jean-Luc is Edward's legal guardian and we provide a certain amount of stability and continuity for him."*

I took on the position of helping him with the medical profession. I pushed him into seeing Dr. M., an endocrinologist at the Geneva University Hospital, for the hormone substitute. I had read in the research about Klinefelter syndrome that the lack of testosterone can lead to osteoporosis, and a bone density test showed that Edward's bones were thin. I accompanied Edward to see the endocrinologist after the bone density test results were available. In my presence Dr. P. M. asked Edward if he could do a physical examination and Edward said he would rather not. Dr. P. M. said that was alright and started a series of questions. Before you start wondering about how intrusive this over-protective mother can be, I want you to know that I left the room. He started on the hormone substitute and went through puberty at the age of 23. Jean-Luc takes over on visits to the endocrinologist because a lot of it has to do with masculinity, and that is not my area of expertise. I appreciate Dr. P. M. and the nurse-practitioner, Mrs. P., who administers the hormone substitute by injection every three months.

I have taken him to the dentist for many visits to have his teeth attended to over the past couple of years. He attends the dental clinic at the psychiatric hospital where the dentist, dental hygienist and assistant are empathetic and supportive. I sit with a book in the waiting room. The benefits system pays for this treatment

and demands that he is checked by their dental consultant. I have gone with Edward for those check-ups. The second time I went in his surgery for the check-up. It is perhaps not habitual that a mother accompanies her twenty-six year old son, but I found out that the dental consultant had been rude to Edward the first time we went. After the first time, the benefits system agreed to the deconstructive dental treatment only.

On the second time, with me present, the dentist says in an unkindly manner to Edward, “your teeth really are in a mess.” I ask him, “do you know about Klinefelter’s syndrome?” He replies that he doesn’t. So I tell him that Klinefelter leads to teeth decay, that it is not just a question of personal hygiene. He glares at me. Then he asks me if this Mr. S. (Jean-Luc) is a lawyer because his letter of complaint to the benefits system about the dentist’s handling of Edward was forwarded to him. Edward replies that Jean-Luc is not a lawyer, he is Edward’s guardian and step-father. The dentist finishes his examination. Two weeks later Edward’s reconstructive dental treatment is approved of. We are rewarded with a smile of white teeth.

We have this kid’s back covered. We cooperate together, Jean-Luc, Edward and I. Edward’s mother did not come into being on her own. Many experiences contributed to constructing her. She was also constructed through the support of Jean-Luc and Edward and the friends, family members and the few professionals who offered their empathy and advice along the way. She is visible in action.

6.2. Conclusion – Being enabled because of my experience

In this chapter I have described thirteen different voices of mine, which came to be through the submersion within cultural dominant discourses and have developed within the relationships that I have had. Had I not been a mother, I would have developed other selves. To do this work has allowed me to give voice and value to the various selves of motherhood, and in particular, Edward’s Mother.

In closing this part of the chapter, I want to include what Michael White has said about how we can incorporate what we have been through and how it can enable us. He writes about his work with a young man, Liam, who had been through a difficult time that included many rejections (White, 2007: 75). He writes, “When I asked him about the implications of this for his future, Liam concluded that future rejections were less likely to be a hurdle to him than they might be for many others. This constituted a new realization for Liam that was particularly important to him – that he was uniquely abled on account of all that he had been through, rather than disabled. Although we would continue to lament the abuses that he’d been subject to for a good part of his life, we were all able to celebrate these conclusions about Liam’s uniquely abled status.”

This perspective allows me to find some peace, some reason for having been through the challenges that I have faced, and by writing about them in this dissertation. I find myself “uniquely abled” in the sense that I can be in ways that I would not be able, had my life been different.

Chapter 7: Reflections and discussion

In this chapter, I reflect on the journey that I took while undertaking this inquiry, and on a number of themes that I have found worthy of further discussion.

7.1. A pause at the start of my reflections

At this point in time, I stop to reflect on this work and on various points that surface. I am close to exhaustion, a state that has been a close companion during this past year, 2012. There are lots of things to be grateful for the year. I am aware that an attitude of gratitude is more helpful than feeling frustrated or confused. I was able to earn my living, pay my tuition and dedicate more than four months to writing. I have written in places far from home. I have not written much in my home office at all. There are too many diversions, too many opportunities to digress into work-related projects at home, things that I can finish in a relatively short amount of time and receive acknowledgement for my accomplishment. I have a “writing corner” in our mountain chalet that has undergone changes as well. I have a bookcase made by my husband that holds the many books and articles I have consulted. I have boxes of letters and documents, now all carefully filed after they have been read, translated, and incorporated into my story. I have also written in Durham, in a house in the woods, covered in blankets to keep the chill of February off. I have written in the December heat of Capetown in the dining room of a guesthouse, with earplugs to dampen the voices around me. I have written in Tielman and Margot’s house in Johannesburg. I have written on the terrace of Vivi’s restaurant, in the breakfast room at Katarina’s guesthouse, and by the roaring fire at Manolis’ cottages in Crete. This work has stuck to my skin, sucked my energy at times, and bit by bit shown me a different way of seeing my story.

7.2. A “pragmatic truth”

I ponder on what kind of “pragmatic truth” (McNamee, 1989) I have written here, and whether it is sedimented, i.e., too “steadfast and secure” that freezes all meaning, which would allow “little possibility for deviation and transformation” (Gergen, McNamee and Barrett, 2001).

I wonder what messages I am sending out about the work that I have written and whether I am aware of all the interpretations that others will make of my work. I fear being criticised for having written what I have written about a subject that may not interest many. This is perhaps a moment of vulnerability, that some will say, “who cares about this subject?” I feel the tears prickling in my eyes as I write that. Carpenter & Austin (2007) write about mothers being silenced when their insider knowledge of ADHD is not acknowledged by the professionals. What implores me to be silent is the fear of criticism of talking up

in the academic and professional world. I have no issue with divulging my personal life in my story (Appendix A), or perhaps I should say that differently. I have little shame linked to the disclosure of personal feelings, of events with others or the reports that were written about myself and my son. I know that I resist being silenced by writing what I have written in my story. I wonder whether others will read that story and interpret it through the perspective of psychoanalytic or psychological theories and methodologies, and turn me into some “monster mother.” So be it.

This dissertation is the report of my inquiry. It is my representation of a world that I inhabited, but a representation that I hope fits the expectations of the academic community of work and be deemed relevant. It is no easy task to walk between the practices of academic literature and experiential accounts. So my dissertation is a cobbler’s work of autoethnographic style that allows for my experience and feelings to melt into the academically required dissertation format. I remind myself of Pearce’s (2007) invitation to write and read ethnographic accounts so that we understand the experiences of others.

Have I met the expectations of social construction to write in a way that demonstrates my knowledge of the moral orders of others? I am not sure. Do the mothers’ stories in Chapter Five of how they were helped by the professionals balance out the stories where they were not helped by others’ remarks? Have we insisted that they are professionals who are helpful to mothers? Have I acknowledged the help and support that I did receive from various professionals?

Does my pragmatic truth, my story, sound too sedimented? Social construction allows for the restorying, the ongoing fluidity of stories, and I hope that I will be allowed that possibility. Will I be seen as having only one story? Or will I be allowed to change it as I continue to reflect and inquire, even perhaps to write about it? Perhaps having written this story about these experiences will allow me to hold my own position “while simultaneously remaining open to the (often oppositional, contradictory) positions of other(s)” (McNamee, 2008). My goal is that we should continue to explore ways of supporting mothers whose children are in difficulty, and that we should inquire or research into such practices so that they become available to those whose moral orders require evidence-based practices. If my goal of supporting mothers is what is important to me, I have tried and will continue trying my hardest to adapt my language and methods in order to influence others in the direction of support to mothers.

7.3. Telling a difficult story in a “nice way”

Tal describes bearing witness as an aggressive act, “born out of a refusal to bow to outside pressure to revise or to repress experience, a decision to embrace conflict rather than conformity, to endure a lifetime of anger and pain rather than to submit to the seductive pull of revision and repression” (Tal, 1996: 7).

How do we tell others of what we have experienced when, to some extent, we hold them responsible for what has happened?

I am reminded of the story of Elizabeth in Pearce (2007:186-188) who had given up working for the Equal Rights Amendment because of the way she came to be described in the terms of defensive, strident, angry and shrill. She found she couldn't change the pattern of communication, and trying to remain the person she wanted to be she withdrew from a cause in which she believed. This is what some would call being silenced, or Tal (1996) would call being repressed.

Are we aggressive when we bear witness when we tell what we have experienced? Pearce describes the discourse of victimization, in which "storytellers manage to portray themselves as the victims of other people's cruelty or of complex conspiracies" (2007: 212). This discourse, he writes, allows the victim to not accept responsibility for what happened, and even to commit evil acts against those, they believe, who were their perpetrators. I am confounded by this notion. I find myself reduced to this label. Is this the only discourse that we have about people who have been subjected to dominant discourse that has made their lives difficult? I think of McNamee and Gergen's (1999) invitation to relational responsibility whereby we are enjoined to bear joint responsibility for the coordinations that are part of being in a relationship. I know that I have encountered doctors and other professionals who have been supportive, positive and encouraging, that they have been subjected to medical discourse that positions mothers in a particular way and that they have resisted that particular discourse. I know that I and other mothers have the right to leave the relationship with the professional who does not meet our expectations of support and encouragement, something that others may call a "consumer attitude." It is a possibility. I know that it is possible to stand up for my son as "Edward's mother" when professionals may be abrupt and inconsiderate, but it does not necessarily invite the other into a dialogue. I was once asked by a group of doctors why I had not challenged doctors more often, and I asked them how they react when a patient challenges them. They admitted that they could withdraw support from a difficult mother. I know that part of what drives Edward's mother's voice is a sense of hurt and anger, and I know that it does not help to answer professionals in the way that they sometimes address me. I have to push myself by asking, "How can I keep from being taken over by hurt, hopelessness, anger or disrespect?," "How can I keep myself from just shutting down?," some of the questions that Roth (in McNamee and Gergen, 1999) invites me to reflect upon before I revert to an attitude of blaming.

I find myself consoled by Lannamann (in McNamee and Gergen, 1999: 89) who writes about the politics of relational responsibility, and asks, "[w]hat kinds of transformations can be brought about by a relationally responsible move when the initiator of the process is in a subordinate position relative to the other?" Lannamann recognizes that the dominant party can ignore the relational

processes (in McNamee and Gergen, 1999: 91) that the person in a subordinate position uses to address them. Hélène, one of the mothers and president of the ASPEDAH association, says that she can work together with the doctors because she acknowledges the difference between medical and parental expertise, and that she is no longer positioned by the doctors as “just a mother of a child in difficulty.” It is also a possibility that the mothers who have accompanied their children, perhaps, out of difficulty and/or to adulthood can become role models for mothers with younger children, and part of support groups.

Rose (2008) encourages users of the mental health services in the United Kingdom to become researchers, to share their insider knowledge in face of the resistance of the medical community. I am appreciative when I imagine that this group of people who are considered “mad” conducting research about the services. This is also a possibility of resistance, of taking action, of joining a group of similar people in a quest to inform professionals. Shakespeare (2006) also models and promotes the idea that disabled people should become part of the medical services that define the needs of the disabled and the provision of services and support. Shakespeare states there is a need to include disabled people in the professions, that their historical exclusion has fuelled “the lack of understanding and mutual respect.” (Tom Shakespeare is the author and editor of the World report on disability and is part of the team working on the launch and implementation of the Report.⁹) For disabled people to enter the medical professions would be “[o]ne way of challenging the tradition of domination.” He talks of the importance of replacing this with “relations of partnership” (2006: 193) whereby the disabled people’s voices are heard when defining the needs and the provision of services and support.

When we do research about ourselves or others to show how our lives are difficult, or have been made difficult by others, how do we portray them? Bourgois (2002: 19) writes about his difficulty in portraying the people he studied in his ethnographic account. He chose, like I did, to exclude certain stories because “[u]nder an ethnographic microscope everyone has warts and anyone can be made to look like a monster.” He also quotes the anthropologist Laura Nader, ‘Don’t study the poor and powerless because everything you say about them will be used against them.’ The experience of inquiring into my life and other mothers’ lives and reporting on my inquiry has been liberating. It has allowed me to see the cultural discourses that abound, and not hold individuals responsible for being part of the discourses (McNamee and Gergen, 1999: 15-16).

⁹ Taken from Swsd2013.creo.tv/Monday/tom_shakespeare/d2p5-shakespear video of the 2012 Joint World Conference on Social work and social development : action and impact, 8-12 July 2012, Stockholm

How can we change the patterns of communication (Pearce, 2007) between professionals and the mothers of children in difficulty? One of the questions that came to me during this work is, how did it come about that we seem to be locked in conflict over the children and our parenting with the professionals rather than united in supporting the children who is different?

7.4. Anticipating professionals' reading of this dissertation

I wonder how this dissertation will be received. A psychologist I know who has read excerpts of Chapter Five said to me in an energetic way, "I hope I haven't talked to clients in this way." I hope so too. I question the need or the approach of pointing out the problems, difficulties or disagreements in order to invoke the need for change. It is a way of getting attention. If I were to write a dissertation focusing on everything that went well, would it inspire change? I wonder. In the defence of the professionals, I could say that when parents are upset and confused about their children, they seem to focus on what professionals say that might sound like a reproach, a criticism. My work has shown that parents do hear the positives. The mothers do pick up on the remarks that recognise what they are doing, and do find them helpful.

I wonder how I will be able to help doctors to talk to their patients in more helpful ways, beyond writing this dissertation. Since starting this work I was asked to talk about my experience as the mother of a child with a variation of sexual development during an elective course for medical students at the Cantonal Hospital of Vaud in March 2012. One of the courses learning objectives is that the students learn how to conduct an open and transparent discussion with the parents of a newborn infant with a variation of sexual development. There were three of us who were invited to share our experience. Two of us were mothers; the third person was a young woman with androgen insensitivity syndrome. We were open and transparent. The majority of the students sat there, looking embarrassed, while one, in particular, with all the grace and tact of a puppy dog, asked us one question after another. We answered all their questions. We all cried and were left speechless. It seemed to me that they were all focusing on getting what they considered to be the right information, i.e. the medical information. I wonder now if we could have asked for their feedback, what did our sharing of experiences do for them, so that they could have given something back to us. If I knew that my information was helpful to them and for the parents they will talk to in the future, but I am not sure. What the students didn't see is that Dr. Meyrat walked up to me as I was tidying up my notes and laptop, touched me gently on the arm, and said, "I'm sorry. I didn't know you had such a hard time." In everything I have read for this dissertation, I have not found anyone who promotes the language game of saying sorry. It is different than apologizing. Apologizing for a mistake or a misunderstanding is another form of language game, but also one that doctors and professionals could offer to mothers and parents. This is perhaps a joint-action (McNamee and Gergen, 1999: 13-14) that has not found its way into the

habitual conjoint relations of doctor and patient in the Swiss French medical system. I find myself wondering about the teaching methods of the course, and whether the learning objectives could include one about having an empathetic discussion with distraught or confused parents. Dekker writes that there are “‘I’m sorry’ laws” in the US States of Oregon and Colorado, whereby “doctors can say to patients that they are sorry for the mistake(s) they committed,” and this statement cannot be used as evidence in court (2012: 69) should the doctors be prosecuted. Perhaps this is a practice that might become more common.

I find myself wondering about the possibilities of using Appreciative inquiry (Cooperrider, 1999; Whitney & Trosten-Bloom, 2003) to hold a summit, or a World café (Brown, 2005) or using Future search methodology (Weisbord, 1992; Dixon, 1998) to hold a conference where we would have the whole system, i.e. all the people concerned, present in the room to find ways of creating a better social world for the children who are positioned as being different. I have used these methodologies for many of my corporate clients. These methods that are underpinned by social constructionist premises are available. How do I create the moment? Perhaps the time will come when it is appropriate to propose such an event.

7.5. My portrayal of the other mothers – politics of representation

As I have written my story and I now read it again, I wonder whether I have portrayed the other mothers in a favourable light and allowed them to have their voices be heard (Gergen, 2009). They gave their permission for me to use their stories, and then they gave me permission to publish their stories (Lindley S., 2011), and I continue hoping that they do not regret their decisions.

Within the scope of narrative inquiry methodology, it therefore seems to be more relationally responsible for us to be attentive to how our formulated questions invite answers. It is not just a question of looking for positive experiences that we can focus on, but of making the inquiry process with our participants as helpful and useful as can be. Our inquiry process is a conversation with other people, who should not be relegated to serviceable others, useful for the duration of data gathering. In my inquiry with the mothers, I found mothers who were eager to participate and to talk about their experiences. They were prepared for the interviews with the three questions. They were introduced to me by a trusted colleague, or we knew each other beforehand. These mothers also knew that I was “one of them.” This was also a wonderful experience for me, learning about motherhood as others experience it. Here were a group of mothers who had similar experiences to me with professionals. And I who had been rarely immersed in the conversations that mothers are “supposed” to have constantly with each other, I found myself captivated by their stories. When I was transcribing the stories, I found myself enjoying listening to their different voices, noting their ways of talking, the

things that upset them, the way they laughed off certain things, or when their voices broke or went squeaky and I remembered their tears. I thought these women are so brave, so courageous and perseverant. There was an overwhelming sense of sisterhood, as I have written already, which was also a novelty. I have often felt an ease talking to women, but not having been a stay-at-home mother I had my prejudices about them as well. My husband has often remarked that I have a knack of chatting with other women as if I had known them for ages when we have travelled around the world. These interviews were not the same way of connecting. Here I was being transformed by developing a deeper awareness of solidarity.

To some extent, these mothers are experienced interviewees. They have become used to describing their children's experience. They also saw themselves as helping other mothers by telling their stories, by bearing witness of their experiences. In Chapter Five, I have written up their responses to the question, "was it helpful to have this conversation?" It seems that it was helpful for all of them. I haven't recorded Marie-Jo's response, but she made a comment that touched me on October 1, 2011, when I was invited to join the ASPEDAH committee and volunteers' meeting to discuss doing workshops for the parents in the different cantons. She was one of the first who said that she hoped that I would come to the canton where she ran the support group for parents. She said to the other people, "every mother should have the chance to talk with Kate. It does good to talk with her." Pearce (2007) and Riikonen (in McNamee & Gergen, 1999: 146) talk about "good communication" being relational. Good communication is not about transmitting our ideas clearly, but making meaning together and making better relationships. The same can apply to the communication within inquiries and research. Perhaps good research is not about gathering clear and factual data, but improving communication between people. If that is the case, then I will continue to inquire.

7.6. How can I continue to help mothers?

I am aware that when the mothers shed tears during the interviews and talked about reliving those difficult times, that it could be considered that I invited them to relive what others call traumatic experiences. In the first workshop I ran for the ASPEDAH association in October 2012 on "What to do with mothers' guilt?" I was attentive to being respectful. I rehearsed my presentation beforehand in front of two mothers and my daughter. Some of the things that were considered helpful by the participants were the following:

- To invite them to introduce themselves to each other as they sat waiting, and to introduce myself and chat with them.
- To invite them to see the possibility of re-storying one's self in a different way. I invited them to describe themselves with words that they preferred. They told me they were courageous, persevering and resilient.

- To invite them to externalise their experience of “mother’s guilt” by giving them a list of questions to describe it. I drew a picture of a woman on the flipchart with a cloud around her head, burning cheeks, a heavy weight upon her shoulders, a knot in her stomach and shaky legs. This exercise is based on the statement of position map 1 that I learned in Narrative therapy training in October 2010 (workshop hand-outs, Institute of Narrative therapy UK). I asked them “what does this ‘guilt’ say to you?” and invited them to talk in pairs or trios, before I elicited them and wrote them on the flipchart. They laughed together as they told each other what their ‘guilt’ said to them. They said that guilt told them, “you should do and you could do differently; you made a child who is different; you should find the right way to treat this child; you should stop shouting, are you neurotic? you should get yourself into therapy; the problem is you; you aren’t capable.”
- To invite them to explain what expectations mothers have to live up to. Again I invited them to talk in pairs or trios, and again I heard laughter. Again I wrote up these expectations. They told me the expectations are, “to be available day and night for your children; to get up in the night and soothe your children; to stay at home to look after her children; to go to work or to look for a job or to be studying; to give her love unconditionally; to not shout, but master her emotions; to love and show that she loves; to teach her children politeness and courtesy; to let her child bear the consequences of his or her actions; to transmit a sense of responsibility.” We noted that some of the expectations contradict each other, for example to stay at home and to go to work.
- To look at the expectations and to see how they are based on norms or standards, which are specific to the culture we live in. I invited them to think of norms that had been established either in the past or in our culture and that were changed. I presented the norm of breast-feeding and how Rousseau had been influential in persuading women to stop the practice of using wet-nurses in the 18th century (Badinter, 1980; Blaffer Hrdy, 1999). I presented the notion of the ideal of the self-sacrificing mother, introduced by biologist Herbert Spencer in the 19th century, based on the idea that mothers should emulate animals as they were closer to nature. I showed them Blaffer Hrdy’s (1999) response: there is only one animal who does that, it is a spider, the *diaea egandros*. That made them laugh. I presented the norm of the mother who devotes herself solely to looking after her children by herself, and who is not only responsible for her child’s physical well-being but psychic well-being, a notion made popular through the work of Freud and other psychoanalysts in the 20th century. And then I presented the Efe community in Zaire where, a research shows, a child has between 5 and 24 caretakers, familiar and willingly available people (Schaffer, 1996: 136-7).

- To reflect on which discourses are important to them, what values are inscribed within those discourses, and to think of the practices that are linked to their values. This exercise is based on the Statement of position map 2 that I learned in Narrative therapy training (October 2010, workshop hand-outs, Institute of Narrative therapy).
- To tell me what idea they were taking away with them, what idea caught their interest. One mother told me that it was while they were talking about the expectations that she realized all the things that she does for her son, and that made her think that she was a good mother and didn't need to be experiencing guilt. Beaudoin (2005: 34) talks of how people who have experienced what some call trauma can discount the actions they took, which renders them meaningless. In my view, in both the interviews and the workshop, when the mothers talked about all the things they did, and that I transcribed all their words and gave the texts back to them, they came to story those actions differently. Beaudoin writes that "[t]herapeutic conversations must make visible that a person's identity is determined by their own choice of action" (ibid: 35). Beaudoin also writes of actions that have not been noticed and not been recognized, and that by acknowledging a large number of actions that were taken, the person may start to appreciate these actions and herself more (ibid: 36-37). When Marion, one of the interviewed mothers, was leaving at the end of the workshop she said to me that she had come to think that she suffered less from the experience of guilt since our interview in July 2010.

This is one way in which I can help the mothers of children labelled with ADHD. I hope that these workshops will help mothers to share, listen and acknowledge their experiences. Hélène, the president has said that the mothers are averse to hear others' stories in meetings, but they do not share their own stories easily. I know of one support group that Mélanie described where there is a lot of sharing, and it is considered helpful. The association ASPEDAH has requested further workshops on "what to do with mothers' guilt" for 2013.

Assuaging the experience of mother's guilt will perhaps increase their possibilities. If the mothers feel stronger, they will perhaps be different in their future coordinations with professionals. They may feel comforted and appreciated by all the actions that they have taken, restored themselves as they would prefer to be, and have a greater sense of agency. What I would hope for is that mothers would be involved in defining their needs for support and in designing the provision of services that will be supportive of them. I often am reminded of Rose Evison's (private conversation, January 2, 2013) ideas of support and challenge, where she defines support as something that the person finds helpful and useful, not what others think will be supportive for you. I am also reminded of Marshall Rosenberg's (1999) Nonviolent communication

method, whereby telling the other how we have experienced the interaction with him or her, we then invite him or her to respond to what we have just said.

7.7. And my question, my quest?

Did I answer my question plausibly about how “Edward’s mother” came to be? I think I did. I think that Gergen’s notion of multiple selves helped me, as did other authors, to find not only a process of how it is that we come to be the way we are, but also a coherent model of multiplicity in our “selves.” I find it an easier way of imagining the possibility of personal change. As McNamee and Gergen (1999: 12-13) point out the notion of “internal others” allows to address our other “selves” that are perhaps suffering, and not being heard. However, there are also other selves that exist in other conjoint relations that can be called upon to help in difficult situations. Edward’s mother also existed because of all the training and reading in interpersonal communication skills that were learned in my professional domain.

I would hope that the popularization of these ideas would open up possibly different, more beneficial ways of thinking about our selves, the situations that we find ourselves in, and the seeking of solutions together with others. As an example, I draw on Seifert (2010) who writes about some of his patients who developed useful personal narratives that included the sick self, rather than deny it (ibid: 47). One of his patients, Leslie, creates new stories about herself. He quotes her saying, “Even now I talk to myself about who I am going to be today. I play around with it all the time. I have an ‘under’ personality that is angry, selfish, needy, and an ‘over’ personality that’s controlled, created – the calm, caring person who is supportive of others. [...] My solution is to be the person I’ve created. I take pleasure in the masquerade.” Seifert writes, “Leslie places emphasis on the performance aspect; she’s an imposter who wears costumes, recites lines, plays roles. But I think her self-description leaves out another truth: that the roles she plays are also her. [...] I think the best solution is sometimes a complicated one, involving play, adaptation, experiment – that ‘fluidity of identity’ I mentioned before. We all harbour different selves inside” (ibid: 127-8). Leslie’s “fuck-you attitude” becomes one of her selves, not an essentialist self that excludes other selves, but one that helps her resist being positioned in the role of compliant, grateful patient. Edward’s Mother also resists being positioned in such a way. I am also inspired by Munt (2007) and Tilsen’s work (2010) with people who call themselves “queer” who have claimed the very word used against them to celebrate their difference, and to inquire about what is meaningful to them. It is also possible that we could turn the meaning of the term “mother’s guilt” into something quite different.

There are moments when I wonder how it came about that I have pursued this inquiry about Edward’s Mother for nearly four years. I am astonished at my perseverance. There are various things that made me continue. I would hate to be considered a slacker, and seeing that I announced that I was doing a PhD I

feel I can't be seen to either give up, or not be able to do it. I also have been intrigued, amused and grateful for the privileges granted to a doctoral candidate. Telling a medical doctor that you are doing a PhD opens the door to conversations that you would not be able to have otherwise. It allows me to continue to be curious and inquisitive within a purpose. It has allowed me to take time off work to pursue my studies, to read endlessly and to reflect on what is happening in the world around me. And there is a notion that I might be taken more seriously once I have a PhD by those I may wish to influence, to invite to take part in a continuation of the conversations or ideas that started with this PhD.

7.8. My journey of restorying – my transformation

When I came to do this inquiry I was originally looking at understanding my different voices, in particular the voice of Edward's mother. I was not particularly interested in studying motherhood. I had studied child development during my bachelor and master degrees in psychology. I had read feminist accounts of womanhood and motherhood. The accounts of Badinter (1981) and Blaffer Hrdy (1999) were the first two books on motherhood that opened my eyes to the historical and cultural situated analyses of motherhood. This was exciting to me. At that point it seemed important to understand the dominant cultural discourses that surround us, that position us as mothers. There is something reassuring in finding alternative stories to the stories. Blaffer Hrdy impressed me with her sense of humour. Being able to see the funny side of theories and other stories seems to be an effective story, and that is what seemed to happen for me.

I have already told you how I experienced the interviews with the mothers, and how I came to be connected with them, finding a sisterly solidarity. It was a welcomed break from reading, translating, and writing up the documents that left me feeling so frustrated and sad.

Then to turn towards understanding the moral orders of the medical profession, under the guidance of Sheila McNamee, I delved into reading Lupton and Montgomery, and others who have written about the culture of medicine. I found myself raging, and picking out the most incriminating quotes that I could find to highlight their disregard for women and mothers. I re-read the feminist accounts of Rich, Greer, de Beauvoir, Millett and others on women and mothers and let anger against the medical profession be my companion for many months. Kleinman (1988), Frank (1995) and Seifert (2010) reassured me that there were doctors who were compassionate.

When talking about this experience and how it came to be, I can relatively easily describe it as a defined number of steps. It has not been a continuous step-by-step process. It has been messy. I found myself reading the same books again because I had not taken notes. I found myself copying out documents that

I had already copied. I hardly dare tell you all the silly things I did which made me start over, you may conclude I am also a silly person. But remember, I am not only a silly person even if I can be that. However I could resume my different activities as re-iterative stages.

- Being confused about the messages from other people about what kind of mother I should be
- Being invited into a stance of “guilty mother” in conversations with others, and how this stance or position swept me up into a position of self-doubt and applied pressure on me to keep on doing more things
- Observing the local dominant cultural discourses’ effects (or experiences) on other mothers through our interviews
- Researching the effects or notions of “guilt” and “shame,” finding the notion of “mis-taken shame,” looking at blaming and shaming as “political acts,” that benefit some and disempower others (Jenkins, 2009)
- Researching other accounts of motherhood from sociobiological, social constructionist, feminist perspectives which allowed me to have other perspectives
- Inquiring into research done with mothers who have children in difficulty, children with learning difficulties or intellectual disabilities
- Researching social constructionist ideas, critical social psychology, sociological social psychology, positioning theory, identity theory, symbolic interactionism, narrative therapy and communication theory to find other ways of inviting people into conversations to construct other meanings that are more empowering
- Writing my story, restorying my experience, making my “unique” sense of reality, which has reduced my personal confusion, and allowed me to see a way forward out of my feelings of suffering, guilt, shame and anger.

7.9. The stirrings of a support group for parents

In September 2011, I attended a conference organised by Pro Infirmis, the largest non-profit organisation or association defending the rights of disabled people in Switzerland. The conference organised for the public-at-large was to provide information in view of the upcoming federal governmental debate on legalising pre-implantation diagnosis of embryos, which could lead to an amendment of the current federal law on medically assisted procreation. There was an impressive list of speakers, who covered the topic from virtually all perspectives. Professor Axel Kahn talked of the historical background and women’s rights movements. Dr. Graziano Pescia, talked about the development of the embryo, and the mutations and malformations. He said that in Switzerland the 2009 statistics showed that of 78’000 live births out of an

estimated 120'000 pregnancies, three thousand children were born with congenital anomalies. Of the women who had pre-natal genetic diagnosis, and were found to have an embryo with trisomy (Down's syndrome) 78% chose to have an abortion. In these cases, the abortion is not called "une interruption volontaire de grossesse", but "une interruption médicale de grossesse". He said that his 'take-home message' was that 3-5% of newborns have congenital anomalies, and that only about 50% have a genetically identifiable cause. We will continue to bear children who have some form of handicap. It starts to sink in, that the discussion today is not only focused on what is possible in terms of technology, but what effects this technology will have on society, and how we talk of those who are handicapped. If such technology is possible, and is not used for whatever reason, how will society treat those who are born with a handicap. I think of Shakespeare (2006) who writes that the majority of people with handicaps acquire those handicaps after birth, like my brother, Matthew, who had a spinal injury at the age of 26. After coffee break, we listen to Charles Joye who explains the legal issues, the legislation that can be amended, and the constraints of human rights. He addresses the common fear of eugenics, the fear that the state may interfere with people's rights to give birth. He talks of the lack of coherence in the current law, that permits a woman to abort an embryo after pre-natal diagnostics (DPN) but does not allow pre-implantation diagnosis of embryos (DPI). He says, we use women's bodies as testing grounds. Alex Mauron, talks of the medical ethics involved, and starts by asking are we more ethical in Switzerland because we allow DPN, or are the Belgians who allow DPI more ethical?

During lunch, I talk to Dr. Pescia. We have a common acquaintance. I introduce myself, describe my situation with my son, and say I would like to talk with him about genetic counselling to understand more about it.

In the afternoon, there is a group of people on the podium who take turns in sharing their stories. Alexandre Jolien, philosopher and author, has cerebral palsy. He is well known and respected in the Swiss-French region for his books. He talks with difficulty to start with, hesitating, and then his speech flows. He talks of the social handicap, "I suffer from the looks of others". He talks of the balance between the ideology of progress, which pushes him to exhaustion, and the difficulty of accepting who he is. He ends his talk with, "I should never be blocked by what I am, I should accept what I can become." It is the first time that I hear him talk, and I am thrilled. He is followed by Emmanuelle Seigner, a mother of a handicapped child, who tells us, "I came here to tell you that I don't know what to say. How can we choose, how can we decide on the value of one possible life? How can we answer these questions?" Alain Kaufmann, lecturer at the university of Lausanne and director of the Ethos Interface group, talks of the deterministic and obscure desire to have a horoscope, whereby we hope to predict the intelligence, sex and characteristics of our children. Sebastien Keller says, "What do we know about the suffering of another person? Whose suffering do we wish to alleviate?" and invites us to reflect on the way we treat

people with handicaps. I think of Tom Shakespeare's talk to counselling students at Webster University in Geneva, who addresses the need for reflexivity of counsellors, and says he wants to do away with assumptions that are not helpful. He says people with disabilities are not depressed and miserable; they generally have a good quality of life, and don't want moral imagination and empathy (Shakespeare, 2011, notes from conference). Sebastien Keller talks of a Swedish practice of support groups for disabled people, whereby parents who have been given a pre-natal diagnosis of a congenital anomaly, can meet parents of children who were born with this anomaly. He says, it is a sort of open house. "Come and see if you like it". It helps the future parents to decide what course of action to take.

During the Question and Answer session, a woman asked a question about the effects of a medical professional saying to a woman, "You are eligible for a medical interruption of pregnancy." Alex Kahn responds, saying that it is indeed a statement that has all the power of the medical expert behind it, and should be, perhaps, formulated differently. I ask the question, "Who decides that it is 'medically recommended' that a woman should abort the embryo that is prenatally diagnosed with a congenital anomaly? What is the process?" Dr. Pescia takes the microphone to reply. He takes the case of the Klinefelter syndrome to illustrate his answer. When Klinefelter syndrome was first diagnosed in 1942, there were many conferences and discussions which resulted in a recommendation of abortion, which was followed by 50% of the parents. It was found that the Scandinavians were less likely to follow these recommendations, and doctors started observing these children more closely. They found that the Klinefelter boys didn't have as many problems as the medical profession had predicted. He states publicly to me that we will start a support group for Klinefelter together.

There were more speakers that day, and I would like to honour them all (Joye, 2012) A politician told us that those who were going to be involved in the decision of amending the legislation would be taking the decision with less information than we had received during the day. It was a wonderfully enriching day, and I had much to reflect upon.

As I think back to that day my companion "dizziness" did not get stirred up by the accounts of personal difficulty, hardships and suffering. My "fuck-you-attitude" was nowhere to be seen. I sat chatting at the break times with a couple whose son has cerebral palsy. He was also present but had chosen to sit with his friends in their wheelchairs and not with his parents. We exchanged stories, we commented on the speakers' ideas, and we were bound together by our insider knowledge as parents of children who are positioned as being different, sometimes in difficulty, but not always.

Chapter 8: Evaluation

In this final chapter, I draw on Denzin's (2003) performative criteria for autoethnographic texts and Richardson's (2005) evaluative criteria for qualitative research.

8.1. Denzin's performative criteria

Denzin (2003) that he values autoethnographic texts that do certain things, laying the ground for performative criteria. These things that he values are the following:

1. "Unsettle, criticize and challenge taken-for-granted, repressed meanings;
2. invite moral and ethical dialogue while reflexively clarifying their own moral positions;
3. engender resistance and offer utopian thoughts about how the things can be made different;
4. demonstrate that they care, that they are kind;
5. show instead of tell, using the rule that less is more;
6. exhibit interpretive sufficiency, representational adequacy, and authentic adequacy;
7. present political, functional, collective and committed viewpoints."

8.1.1. Unsettle, criticize and challenge taken-for-granted, repressed meanings

I think that I have challenged some of habitual discourses about mothers who have children who are in difficulty because they are different. Had I not challenged the meanings that are so commonplace, I would not have had certain reactions, such as being told that I have a "fuck-you attitude" towards the medical profession. This seems to me to be an indication that I am unsettling something.

By asking mothers what remarks they found helpful, they focused on the professionals' remarks, although some did talk about their friends. This turn towards looking at professionals pointed me in the direction of inquiring more into the medical discourses, their dominance, and the literature on mothers' well-being described in Chapter Three. Although I had imagined when I wrote up my first description about my dissertation for the Taos Institute website that I would talk about how mothers have to accept professionals' models and processes in order to receive support, the writing of my story (Appendix A) had also immersed me in husband-wife and teacher-parent relations which could also have benefitted from a closer inquiry.

8.1.2. Invite moral and ethical dialogue while reflexively clarifying their own moral positions

I would hope that this dissertation would be read by professionals who would be interested to take part in a dialogue. I find myself since I have worked on this dissertation asking doctors why they chose to work in their field of medicine. I enjoy reading “disclosures” in text books, and sometimes do an internet search on authors, like Harper (2007), to find some indication of how it came to be that they decided to research a certain topic. I want to know where their passion and their heart connection (McNamee and Hosking, 2012) lie.

I have invited mothers to have moral and ethical dialogue by inviting them to talk about both helpful and unhelpful remarks, to be part of the inquiry and to recognize their contribution through the publication of the texts. In comparison, I wonder about Stuart’s (2007) psychoanalytic based work that focused on women’s relationships with their mothers and how that relationship influences the woman’s choices and the experience of conflict between motherhood and career. What does please me, is that Stuart writes, “[w]ork on this project has sharpened my appreciation of the complex interplay of broader social phenomena with individual psychology.” This does lead me to a recognition of the story that I have presented in this doctoral dissertation, of the angle that I chose to pursue. I have already written that I believe I was respectful, moral and ethical, in my inquiry with the mothers. I wonder what I would have done had one of the mothers not wanted to partake in the interview, not wanted to publish her text. In their sociological study, Genevie & Margulies (1987) surveyed 1100 mothers in the USA through a questionnaire, “to learn how women feel about their children and about being mothers, to portray their feelings in their own words, and to identify the life experiences that differentiate between women who had essentially positive experiences and those whose experiences were less positive.” Their questionnaire of ninety items (ibid: 449-471), many of which seek negative information. I wonder what motivated the 870 women who filled out this survey to participate. I wonder how they felt after filling it out. I wonder how filling out this survey changed their experience of motherhood. I wonder about the 230 women who refused to participate in the survey. It is not that I refuse to acknowledge the report the authors drew up. I have drawn on their work, the qualitative statements, a few times in this work. I do not doubt that the weight of statistics would signify importance in the traditional, positivist world.

Have I clarified my own moral position? I think so. I have chosen to turn my gaze on mothers and the support they receive when their children are in difficulty. I have avoided looking specifically at their interactions or the coordinations with their husbands or their children.

8.1.3. Engender resistance and offer utopian thoughts about how the things can be made different

Through my questions with the mothers, I asked about their reactions, which in some cases, depicted cases of resistance to the gaze of the professionals. By writing about what they found helpful, we also have examples of coordinations that were different, and could be more often possible in the future.

8.1.4. Demonstrate that they care, that they are kind

I do hope that I have been caring and kind towards those I worked with. I do care about the medical profession and the experiences that are created within the coordinations of doctor and patient.

8.1.5. Show instead of tell, using the rule that less is more

Originally my story in Appendix A was the focus of my dissertation. It was found to be full of mundane details, inviting the reader to skip over it. It was not sufficiently critical or analytic (McNamee, personal correspondence). It was a portrayal of life, and life is full of the mundane details and boring repetitions. The second version was full of anger, telling the reader what a bunch of oppressors the medical profession consists of. This version you are reading is the third version. I hopefully have led you through the construction of this dissertation and the inclusion of stories and theories to understand my perspective. It is shorter than the original story: is less more?

8.1.6. Exhibit interpretive sufficiency, representational adequacy, and authentic adequacy

From the original version to this third version, I have started to affirm my academic voice to interpret the work of others in relation to my own experience. I hope that this voice has managed to do this interpretation, this analysis and this choice of focus to illustrate the points I have hoped to make. I hope that the representation of my group of mothers has been sufficient and adequate, so that it is plausible that a sufficient number of mothers with children in difficulty have similar difficulties, which would in turn merit the professionals' attention. I hope that my reflexivity, my openness, my disclosures have persuaded you of the authenticity of what I write about.

8.1.7. Present political, functional, collective and committed viewpoints

I have presented the viewpoints of mothers. I have not presented the viewpoints of the professionals that were involved. One voice of mine refers to Tannen (1998) who says that we do not always have to present the other's case. I would perhaps suggest that the medical profession has shown that they are more adversarial in their presentations, more eloquent in their portrayals of mothers' weaknesses, and I did not wish to engage with them until my moral position had

been sufficiently identified and acknowledged. However, I did interview two doctors, Dr. Burlet and Dr. Junier on March 7, 2011. Dr. Burlet's hope was that mothers and fathers would join the ASPEDAH association openly, and come to defend their children's rights to more adequate educational measures. He said that the Swiss tendency to hide our problems and to treat them only at an individual level diminishes our ability to act collectively.

8.2. Conclusion

I wonder how to answer the questions that Richardson (2005) formulates for qualitative research criteria that I have written out below. I cannot answer these questions in your place, dear Reader. There is only one question that I feel moved to answer, and that is the question under the title of impact. I come back to this later.

Richardson's (2005: 964) criteria includes:

1. Substantive contribution: "Does this piece contribute to our understanding of social life? Does the writer demonstrate a deeply grounded (if embedded) social scientific perspective? Does the piece seem 'true' – a credible account of a cultural, social, individual, or communal sense of the 'real'?"
2. Aesthetic merit: "Rather than reducing standards, another standard is added. Does the piece succeed aesthetically? Does the use of creative analytical practices open up the text and invite interpretative responses? Is the text artistically shaped, satisfying, complex and not boring?"
3. Reflexivity: "How has the author's subjectivity been both a producer and a product of this text? Is there adequate self-awareness and self-exposure for the reader to make judgements about the point of view? Does the author hold himself or herself accountable for the standards of knowing and telling of the people he or she has studied?"
4. Impact: "Does this piece affect me emotionally or intellectually? Does it generate new questions or move me to write? Does it move me to try new research practices or move me to action?"

8.2.1. My cultural context in regards to the substantive contribution

My inquiry has taken place in the Swiss-French part of Switzerland, starting from 1984, the year that I was pregnant and gave birth to my first child. This historically located space of Switzerland, a country best known for its trains that run on time, its secretive banking system and the Red Cross organization, is where I have lived since the age of nine. Its direct democratic system aims to ensure political consensus and stability, which has provided a much-envied economic wealth. However, what is less known to outsiders is that the women did not have the right to vote until 1971, and that it had to be enforced by the judiciary system in some cantons (states). As in many Western countries, there is still much tension regarding the role of women in society. The Swiss-German

adage that women look after “Kinder, Kirche, Küche” (children, church and kitchen), while the men look after the economy and military, is still popular. I fit into this culture where respect for authority, discretion and hard work are admired. The country has four linguistic groups; Swiss-German makes up the majority, Swiss-French is the second largest community, Italian the third, and Romansch, a Latin-based language, is only spoken within a primarily Swiss-German canton. As a child I lived with my parents in the Swiss-German city of Zurich, where I learned to speak the local dialect. My inquiry focuses on the Swiss-French area in which I have lived since the age of 18. My experience recounted in my story (Appendix A) is mainly based in Geneva, a small international city, the other home of the United Nations and of the majestic water fountain. Forty per cent of the population is non-Swiss. It is here that I, like so many other families, find myself in a recomposed family, naturalized Swiss, speaking a mixture of my mother tongue, English, and the locally spoken French.

If I do not accept research as universal truth, then equally I consider that this research is perhaps not relevant elsewhere. However, the experience of mothers described by Malcrida (2003) and Carpenter & Austin (2007) shows that mothers in Canada, United Kingdom, and Australia are facing difficulties similar to the ones that I have depicted.

This inquiry does not draw on Swiss or French research, and it may be considered that some of the points that I am trying argue through the use of literature, e.g. the adversely affected well-being of mothers whose children are different in Chapter 4, under Point 4.6. are not relevant to the Swiss-French society. However, the narrative inquiry into the locally situated mothers’ experiences already published in French (Lindley S., 2011) is being read by professionals in the Swiss-French area. The narrative inquiry that I have done in this dissertation is ready to be translated and published in French.

8.2.2. More questions, more opportunities to inquire in regards to the impact

I am definitely moved to action after stopping here and completing this dissertation. There are many questions that I have, many opportunities to inquire in order to inform.

What are the practices that we have in place to assist the mothers in their challenges of raising a child who is different? I can imagine doing further work and publishing stories of professional practices that are valued by parents. The work can include dialogue with specific professionals who would be interested in understanding how they can support parents with children who are positioned as being different.

How do fathers experience their role as father raising a child who is different? How would they prefer to do this? The voices of the fathers are missing from

this inquiry. Some of the fathers whose wives were interviewed agreed to being interviewed as well. Fathers may also need support. Parental partners may also need to elucidate what form of support their partner prefers.

How about the children? How about those who have been diagnosed and labelled? Can we imagine including children in an inquiry about their experiences? How could these children's accounts of their experience influence adults, both parents and professionals? How could they help other children's experiences by telling about theirs?

How do parents of children with variations of sexual development experience the medical advice and support that is given to them? What is helpful for them? The starting point for this inquiry has already begun.

And that will be another story. Until then, dear Reader, may you be well.

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Appendix A: A Poem by Yvonne Sliep

On August 5, 2012, Yvonne Sliep sent me this poem she had written for me after reading the story that you will find in Appendix B.

To witness
 the end
 from the beginning
To experience pointers
 leading to more stress
 sometimes disaster
To understand
what may have been different
 but not know for sure
No positive uncertainty
in this journey
 only overwhelming unknown
with little support
 and ignorant systems
The confusing relief
of a crippling diagnosis
Explanation making way
for redemption
 The world too threatened
 to offer much
 beyond fascination

Through the cracks
the spirit of Eddy
seeped and gathered
the love of his mother
a constant like weather
 and for now
victory of the ordinary
stillness in the eye of the storm
a moment called boring
allowing Edward and his mother
to more fully be

what is life but to survive
anchored in a story

with deep respect and care,

Yvonne

Appendix B: The story of Kate and Edward

The following is a chronological account of events taken from my letters, personal journals and documents about my life with a particular focus on Edward.

B. Chapter 1: Becoming a mother in 1984

I want to get pregnant

I have a pink flowered notebook, in which I have recorded information about being pregnant, my children's sizes, heights and weights, their illnesses. I started at the front of the notebook with the information about becoming pregnant, and from the back, coming forward, I wrote down the information about the children.

The first page has a small card stuck on it; at the top of the card is the name of my gynecologist/obstetrician, Dr. B., and his address. The card has three charts for recording one's temperature which indicates the time in a woman's cycle when she is the most fertile. When I got married to John in April 1982, I remember telling people at the wedding that I wouldn't be having a child until I was at least 30. And yet here in this notebook I was recording my period dates as of September 1982. It seems that I started to want a child earlier than I otherwise remember. My best friend, Brigitta's first child was stillborn, born in the summer of 1983. I remember when she called me to tell me she was pregnant again, I went to the toilet and I cried. Was I happy she was pregnant again, or was I upset because I wasn't? I also remember John telling me that it was hard on him too when I told him each month that I hadn't conceived. I was talking to my gynecologist about it, because he sent me for an examination.

On the fifth page of my pink notebook, I wrote:

3.2. 84 *Hysterology at 16:00, Dr. Isnard, Clinique des Grangettes*

I look up the word hysterology on Wikipedia and find nothing that corresponds to that word. I do a search on google for "procedures that examine fallopian

tubes” and find a website webmd.com and read through the multitude of procedures starting with laparoscopy until I come to the following description¹⁰:

A hysterosalpingogram is an X-ray test that examines the inside of the uterus, the fallopian tubes, and surrounding area. It often is done to look for a cause of female infertility.

During a hysterosalpingogram, a special dye (contrast material) is injected through a thin flexible tube, or catheter, that is inserted through the vagina and the cervix into the uterus. Because the uterus and the fallopian tubes are connected, the contrast material then flows into the fallopian tubes. As the contrast material passes through the uterus and fallopian tubes, continuous X-ray pictures are taken.

Hysterosalpingogram pictures can reveal problems in the uterus, such as injuries or abnormal structures that may be preventing a woman from getting pregnant.

That seems to depict what I went through. I lay on my side with tubes inserted in my vagina. Next to the examination table I was lying on was a screen and I could see the contrast material advancing into my uterus and fallopian tubes. I later described it as uncomfortable as a period. While I write this, I can remember feeling nauseated and turning the screen away so that I couldn’t watch it. Even now, I feel dizzy-headed and feel my heart pounding. I am not very good with all things medical. I have learned to cope with lots of situations but often I have to lie down on the floor, put my legs up and just breathe deeply until I feel better.

On the same page, I wrote:

8.2.84 Spermogramme at 8:15, Laboratoire Bio-méd, 18, bvd des Philosophes
That seemed to be a less painful and uncomfortable procedure, as I recall.

On the same page, there are two more entries:

17.2.84 Dr. B. at 9:45. Results

I remember him telling us that we were both capable of conceiving a child. One of my fallopian tubes was partially blocked and the examination itself had

¹⁰ Retrieved from <http://www.webmd.com/hw-popup/hysterosalpingogram> on August 22, 2011

apparently “unblocked” it. There was no reason why I should not be conceiving. He proposed that I take Clomid to ensure my ovulation.

I wrote in my notebook:

17.2.-21.2. included: Clomid

Clomid is described¹¹:

Clomid is the brand name for the fertility drug clomiphene citrate. Clomiphene citrate may also be sold under the brand name Serophene. Clomid, the most commonly prescribed fertility drug, is used to induce ovulation (egg production) in women who do not produce ova (eggs) but wish to become pregnant. Clomid is in a class of medications called ovulatory stimulants, according to the National Center for Biotechnology Information. It works similarly to estrogen, a female hormone that causes eggs to develop in the ovaries and be released.

On the charts on page 4 and 6 in my notebook, I can see the graphs indicating my temperature on each day, the days I took Clomid, and the days when John and I made love, indicated by “ML”. I remember feeling unwell during the days I took Clomid in February. However the following month I took it again from the 18th to the 22nd of March, following my period which started on March 14th. According to this chart, I deduct that Edward was conceived in the evening of March 31st when my temperature went up, and John and I made love before going out to dinner with Birgitta and Bernhard. We arrived late, sheepishly.

On page 9, I wrote :

19.4. Test results positive

24.4. Visit to Dr. B. with John

Ultra-son Polaroid of baby: 9mm

Sick with sore throat

Birth foreseen for December 24 +/- 10 days

25.5. Visit to Dr. B.

Ultra-son – baby bouncing

Head to bottom : 27 mm

Weighed with clothes: 58.5

¹¹ Retrieved from <http://www.clomidbirthdefect.com/> on August 22, 2011

*Checked inside vagina with spectrum. Everything ok.
“Sickness should wear off”.*

On the following two pages, there are two photos of the foetus in my uterus.

On the following pages I noted my weight and measurements for June and July.

I wrote:

5.7. Visit to Dr. B.

Baby roughly 16 cm.

Scan Polaroid of head

Saw heart beat

Urine test

2 days off to rest

John came with me.

21.7. Baby kicks for 1st time lightly in gut region. John felt it too.

30.7. Weight 60 kilos

3.8. Visit to Dr. B.

Internal examination. Urine sample. No picture.

August

Holiday August 5-27

During holiday baby's movements can be seen – surface of tum moves about like water rippling. Movement inside continuous.

Tiredness gone.

27.8. Weight 62 kilos

September

Friday 7.9.

Visit Dr. B.

Checked weight, blood pressure and urine.

Ultra-son scan to check baby. Well positioned: head down, body on my right side and bum/legs on left side which is why I feel more “action” on left. I should go on exercising as normal. Next time he'll give me address of ‘birth preparation’ courses. Medical certificate for 70% working capacity.

Sunday, 9.9. 18 kilometers on bike

Tuesday, 11.9. hair cut

Wednesday, 12.9. 12 kilometers on bike

Welti-Furrer, the moving company, brought white cupboard, treasure cot, etc.
Sunday, 15.9. 11 kilometers on bike
20.9. Thursday – aerobic class
22.9. Saturday – bike ride 14 kilometers
24.9. Weight 63.5 kilos

October

Sick, off work 1.10. – 3.10.
4.10. Appointment with Dr. B.
Checked urine, weight, blood pressure
Internal examination
Ultra son to check diameter of head: 7 cm
Birth: foresee inducing baby on December 17
He'll check us into the Clinique des Grangettes
Work as of 5.10. on 50%

Baby in breech position

Preparation classes: S. Extermann rue du Stand, start 10.10., every Wednesday at 17:00
10.10. Course : Labour
14.10. Bike ride 7 kilometers
15.10. Bike ride 9 kilometers

In my letter to my mother, dated October 15, I wrote, “*Your grandchild is pushing hard. I’ve made the one meter mark around the hips. And my normal hip size is 73 cm. That’s some stretching. And 2 months to go!! I started my preparatory course which I find as much fun as Hauswirtschaftsschule (domestic science school¹²) : full of stupid women! I don’t feel like going back, but think the more I know the better. I found out how they induce and the implications and feel happier about that. Which is more use than learning how to cook ramequins with old bread and old cheese ...!!*”

¹² All young women between the ages of 16 and 20 were legally obliged to attend domestic science classes in the canton of Zurich, Switzerland. If a young woman was employed, her employer paid 75% of her salary was paid. I attended class in January 1976, but had to stop after a month because I had mononucleosis, acute and chronic tonsillitis.

From my pink notebook:

17.10. *Course cancelled*

18.10. *Course : Films on breastfeeding*

24.10. *Visit Dr. B.*

Leaked during the night of 23-24 and went for check-up

Baby still in breech position

Weight: 67 kilos

24.10. *Course : Solange – Breastfeeding and breathing*

31.10. *No course*

In early November, I wrote to my mother, *"I couldn't go to London or rather Torquay with John cause my doctor wouldn't let me as we had a bit of a scare last week with me leaking during the night, and thinking it was the amniotic fluid flowing. So now we're on to regular weekly appointments – and vows to take it easy. Thank god, he didn't confine me to bed. We all know what a wonderful patient I make, don't we????? ha ha. Mark says Meroulla's¹³ going to have her baby in November. The head is already engaged. Mine's still in breech position. I'm getting bigger and bigger and bigger.*

At the preparatory course we talked about breastfeeding the other day and the mid-wife said the best bottles are Playtex bottles, made in USA, and of course unobtainable in this deserted part of the world. They are the ones with rubber nipples like a human nipple and have plastic bags inside. I won't say what you do with the plastic bags because John said it made him feel funny to think about so maybe Dad would feel the same way. Could you get me two bottles please? Plus plenty of plastic bags to go inside? Thank you very much. We also started relaxation exercises and breathing exercises and should practice everyday. I have written to Charlotte¹⁴ and asked her if she wants to be god-mother. I feel that Richard¹⁵ can take care of the religious upbringing of the child, but if anything happened to us, I guess my sister would bring the child up in the same crazy fashion that I would."

¹³ My sister-in-law, Meroulla, wife of my brother, Mark, was expecting at the same time. Luke, their son, was born on December 12.

¹⁴ My sister, Charlotte, lives in Philadelphia.

¹⁵ Richard Frost was the priest of the English-speaking Roman Catholic community of Geneva. We had asked him to be Edward's god-father.

From my notebook:

November

1.11. Visit to Dr. B. with John

Baby in breech position

On November 10, I wrote to my parents, “My every-other week letter home! ... I’ve finished my patchwork duvet cover for the baby’s bed and have started another one with sheep on the front. It’s machine done patchwork – not as precise and nice as yours...

I think baby has finally turned around cause my stomach has changed shape completely. Only five weeks to go until December 17. We’re doing breathing exercises in class. The doctor says we should call the clinic and go round to see the birth room and have everything explained to us. They still shave!!! And you get your cup of tea up your you-know-where too¹⁶. I feel so unprepared, but the mid-wife says that nothing will prepare us for it anyway. John is worried and thinks I’m very courageous – not much option is there???

Only three more weeks of work to go and then twelve weeks off. Seems strange that I won’t have to bother putting a skirt on and getting dressed up for 12 weeks. I’m sure it will go all too fast.

Looking forward to seeing you after Xmas. Have you any special wishes for Xmas presents? ... Get your order in early. There’ll be a rush around here at Xmas. ... Could we have present that have nothing to do with cots, nappies or whatever? I would like a year’s ration of poptarts!”

From my notebook:

16.11. Visit to Dr. B.. John says he talked of “elle” (her).

Baby’s bottom firm on my bladder, legs “en l’air” (up in the air).

Not very comfortable. Talked of possibility of caesarean. Will decide on 3.12.

Medical certificate for 100% as of 19.11.

Last working day: Friday, November 30

7.11. Course with Elizabeth. Birth relaxation exercise.

14.11. Course: Birth positions, Doctor and insurance for baby

18-19.11. Contractions

¹⁶ An old joke told in my family about a hospital patient asking for a cup of tea and receiving an enema in its place, albeit in the “wrong place”.

21.11. *Relaxation exercises*
 22.-23.11. *Contractions*
 23.11. *Started a cold*
 23.11. *John's foot in plaster - out of plaster* 30.11.
 25.-26.11. *Contractions. Had to get up 3 times. Tummy so hard and pressure on bladder so great.*
 28.11. *Course : Layette for baby*
 30.11. *Course : Birth position practically done and explanation of baby coming out. Fathers attended. John came.*

On November 26, I wrote to my parents, "*All Xmas presents are now purchased and I'll send them off tomorrow. What organization! I'm getting in a panic: there's so much to do before going into hospital. This is my last week at work training a girl to do my job. At least I've got somebody with some brains to hold the fort. I've come down with a monstrous cold and baby is now horizontal. We're seeing Dr. B. on Monday, 3.12. at 2:30 and will decide then*¹⁷. *Will call you or let you know by telex what is decided, cause a letter won't make it on time. In any case, I'll be at the Clinique des Grangettes, 12?? Geneva. Tel. 022/4911 22. I'm hoping that John will be able to stay with Birgitta*¹⁸ *and Bernhard cause they're just down the road. ... Looking forward to seeing you both soon. Have found two reliable babysitters already so we can go skiing on Jan. I*st *! One for the baby and one for John*¹⁹ *Lots of love, Kate, John & Orson Welles"*

From my notebook:

3.12. *Visit to Dr. B.*

Baby sitting on bladder yet seems to want to move around.

Ultra-son done. Baby's circumference of head 8.5 cm

Urine test

Weight 70 kilo. Talked about caesarian birth. I don't want to give birth normally if the baby doesn't turn around. Next rendez-vous on December 12 to see baby's progress and take further decision.

6.12.-7.12. *Contractions*

¹⁷ Decision about a Caesarean delivery

¹⁸ Birgitta was my closest friend, a Swedish mother-at-home, married to Bernhard

¹⁹ John had his foot in plaster due to a running accident.

12.12. Visit to Dr. B.

No change in position.

Internal examination.

Ultra son shows baby bottom downwards, head on left side and legs on right side. Caesarian foreseen on 17.12.84. Dr. B. called Grangettes to book operating room. Went to Grangettes to get list of things and papers needed.

John, my husband, and I went to see the film « Amadeus » on December 15th, 1984. It was a Saturday evening. I remember finding Mozart rather wacky and wonderful, being amused by the film and the intermission, which remains the most memorable part. When the lights came up, I heaved myself up with difficulty from my comfortable seat, pushing myself with one hand and pulling myself with the other hand placed on the back of the seat in front of me. On the way up the aisle, an old acquaintance stopped me and said, “hello”. She looked at me in a rather amazed kind of way, as did the other women when I opened the door to the ladies’ toilets. They stood to the side and let me pass, so I skipped the queue to and was the next to enter the first available cubicle. While I waited in line, another woman asked me, “When are you due?” “In two days time,” I answered, “Monday morning at 9:00 a.m.” Silence descended upon the room. When I came out of the cubicle, I saw their faces, looking at me with anxious smiles, and again they stood out of the way so that I could waddle through, out the door and back to my seat next to John. I was wearing a royal blue sweatsuit, my stomach pushing out in front of me, like a ship cutting through the choppy waters, mounting the waves. I imagine that I struck an impressive figure.

The event of giving birth

I have often said that preparing to give birth was similar to preparing to sing an operatic solo on stage. You learn your breathing techniques, you learn how you are supposed to move, you check out the clinic, the birthing room, and then comes the big day! This is the day when it should all come together, and be a “memorable” event. It usually is, but rarely the way you imagined it. If you thought you would give birth in dignity, showing self restraint and control, with loving, supportive people around you, most of us who have been there, done it (even some of us were lucky enough to have the video), have rarely been heard to say that it was a lot of fun. We even pretend afterwards that it was, probably

out of “political correctness” but as a close friend said to me a couple of days after giving birth, “it was a fucking disaster”.

Having a caesarean birth felt like I was hardly needed on-stage, that all control of events were totally out of my hands, that my body had become an object and was manipulated by various people.

My little pink flowered book accompanied me to the clinic the evening of December 16 with the baby clothes my mother had bought for me. I had written down the dates of my periods, my temperature on the crucial days of the month, on the first pages. And then I started noting my weight, my morning sickness, and stuck the first echographic photo in it. During the week following Edward’s birth, I wrote the series of events from Sunday evening to the moment that he was taken out of me and given to me to kiss on the forehead, wrapped in aluminium and taken off for tests by the paediatrician, while the obstetrician sewed my lower parts back together.

This is what I wrote in my pink notebook:

16.12. Sunday, 17:00 check-in

Awful little room.

Midwife came at 17:30 to take blood test and shave me.

We listened to the baby’s heartbeat for the first time.

18:00 supper (bowl of soup and compote de poires).

Had to vomit because of nerves.

19:00 John left. I slept until 20:30. Got up and washed.

21:30 The anesthetist (spelling?) – a woman doctor – came to see me to inform me of what will happen.

22:00 Took sleeping pill.

Awake at 3:00 and dozed until 6:00.

17.12. Monday

No breakfast – just an enema.

Taken down at 9:00 and prepared with epidural.

John in doctor’s outfit.

9:36 a.m. Edward is born.

10:15 taken to intensive care station.

John goes off to make phone calls and returns about 13:00 when I’m taken back to pokey little room.

Reading those notes, I remember my surprise at seeing John scrubbed up in a doctor's gown and mask. I was laid out on the operating table with a screen blocking my view so that I couldn't see over my hump. I was hooked up to the IV apparatus and the anaesthetist looked at me and asked me if I was all right. No, I wasn't all right, I was feeling quite queasy and scared so she popped something into the plastic bag and in a couple of minutes I was feeling better. The epidural anaesthetic did its trick and I was cut open. John watched the incision and reported later that he wondered how they would ever put me back together again.

Later in the afternoon the attending paediatrician came by to see me and Edward. He put his finger in Edward's mouth and Edward clamped down with his gums. He said to me that breast-feeding wouldn't be easy. It wasn't but as soon as I was moved to another room I had a television and when I would put Edward to my breast I would make sure there was something interesting to watch on TV so that I wouldn't pay so much attention to the pain. The pediatrician told me that Edward was diapered in a certain way, in French it is called "langer large", because while he was in my uterus, in the breech position, his legs were positioned in such a way that when he was born his legs stuck out to one side instead of hanging down straight. It was custom to keep mothers who had given birth 'normally' for five days, and mothers who had had C-sections were kept for seven days.

The Daily Telegraph, Wednesday, December 19, 1982
Section Births

Lindley. – On Dec. 17 in Geneva, to KATE and JOHN, a son (Edward)

Home on maternity leave

I left the hospital on Christmas Eve and returned to our small home. It was bitterly cold, -10° over Christmas. Of all the many gifts we received no-one had given us a hat for the baby and I hadn't bought one either. It was not easy to think of going anywhere without a hat. I had very few girlfriends who had children, John said he couldn't take time off to go and buy a hat, so I finally persuaded a friend, Zarina, who worked at the Hilton to buy a hat for Edward during her lunch break and to give it to John to bring home.

In my notebook, I wrote:
Home on 24.12.

Breastfeeding

24.12. 16:45, 19:00

25.12. 01:00, 04:00, 08:00 (bath 10:00), 12:30 and 15:30 (1 side each)
18:00 (2 sides) and 100g water, 21:00 (2 sides)

26.12. 02:30, 05:30, 08:00, 09:30, 10:00 bath, 12:30, 15:30, 20:30, 21:30 (not asleep), 22:30 (sleep)

27.12. 02:00, 05:00, 09:00, 13:00, 14:30 (suckle), 17:00, 19:30. Woke him at 21:30 for 1 side, 21:45 bath, 22:15 other side, 22:30 bed/asleep)

28.12. 01:45, 05:30, 09:00, 10:00 dressed

My brother's wife, Meroulla, gave birth to Luke on December 12th in London. My mother had come over from New Jersey and was still staying with them on December 17th. Mark told me that she had gone to church that morning. My parents went up to their house in Norfolk for Christmas celebrations and came to Geneva to be with us afterwards. My mother had said on some occasions that when a first baby is born, the parents just want to be together with the child without anybody bothering them, and so they had decided not to stay longer than three days. I was in two minds about her coming to stay, on one hand I wanted to show off my baby and show that I was in charge, on the other hand I was silently pleading her to stay and show me how to take care of a baby.

My mother wrote to me after she had returned to New Jersey on January 11th, 195:

First a big thank you for having me to stay and for letting me really share Edward. He really is a lovely baby – and so responsive so early. Seeing two little babes within the month made me realize so much how these little people already have characters and personalities. Mark was there at the airport to meet me with Christopher M. he gave me a lovely greeting – a great hug and a kiss. Little Luke is also waking and shouting at night, but I think he's stretching the sleeping a bit better. Evenings seem to be his social hour.

I had one good friend, Birgitta, who had a four-month old daughter, Gaby. Birgitta had worked in Sweden, her home country, as an auxiliary nurse before coming to join her husband, Bernhard, in Geneva. They had lost their first-born, Patrick, at birth in the summer of 1983, and we had gone to stay with them until their family could come down to join them. Birgitta was a stay-at-home wife and mother. She was incredibly practical and knowledgeable, and I relied on her

advice. In January she invited me to stay with her in their weekend house in Sarnen.

I wrote to my parents on January 19:

John and I went up to Sarnen on the train last Sunday to Birgitta's. Bernhard has been in Hong Kong all week. John left Tuesday morning and I came back on Thursday eve. I was dying to come back. I can't bring myself to like Gabrielle: she's enormous, looks just like Bernhard, dribbles constantly – i.e. if she's not screaming her head off either because she's happy or sad. Hard to define the screams of joy from the screams of complaint. At one point even Edward had enough and cried until I took him upstairs to the peace and quiet. First time that I've had to retreat to breastfeed from company. Nevertheless Birgitta was super and we had a very restful couple of days. I even let little Edward sleep the last night on his Dad's vacated side. Kept me awake all night with his babbling in between feeds.

I had to find a pediatrician for Edward. I opted for a woman pediatrician, Dr. M., who was also a mother, and whose office was not far from where we lived. I wanted to make sure that I had a better chance of being accepted as a working mother, and I thought that a working mother would be more likely to accept me.

I wrote :

We saw the pediatrician yesterday for first time. Edward has grown 4 cms and put on a kilo. Congrats to mother's breasts even if she's a bit fed up. It's a lady doctor, very gentle and understanding, so I'm extremely happy about that. She checked his hips and said she can't feel anything wrong, but will still plan an x-ray in 2 months time.

Told me I was putting a strain on myself by using proper nappies – and it was the first time I'd put one on. Told me I should try to get an extra month off so I can give him 3 full months of breast and that I should get cracking for a crèche²⁰. I called the best one in town and have to call back next week cause they don't know if they have room. Doctor says a crèche is better than a day mother. the social interaction is better, but they get all the colds, etc. The cost of the crèche is 820.- a month and the day mother 550.-.

²⁰ Child daycare centre with facilities for babies

The financial situation was not the easiest. We were working in the hotel industry and salaries were at least 25% less than other industries. I wrote: *We're wondering if I should give up work completely, but I can't see managing on 4'400.- a month when our rent will be going up to about 1'800.- at least and we've still got 900.- a month on the boat to pay till December. I think we'll just have to get through this year and reassess the situation for 1986. Also with John's job situation still up in the air, I think I'd like to stay on working.*

I couldn't imagine giving up working for several reasons. I would not know what to do with my time. I couldn't imagine going to coffee-mornings with other young mothers. Apart from Birgitta, I didn't know any other young mothers. I felt very isolated during my maternity leave from work. The weather was appalling, I couldn't take Edward out a lot, even if I had made myself a cape, on the pediatrician's recommendation and I carried him in the 'kangaroo-bag'. It was hard to exercise after the C-Section. John was working very hard and had taken over the discotheques at the Hilton and was required to work on Friday and Saturday nights, until closing time around 5:00 a.m. There was a day when he came home from work and I threw a woollen pom-pom at him and said something like, "look what I managed to do in a day". Needless to say I wasn't very interested nor was I particularly good at sewing or knitting or cooking. I sometimes said that it was too hard to compete with my mother's wonderful skill in doing all these things. It was perhaps also that I was comparing my results with hers, and found them always to be considerably poor.

Before Edward's birth, I had written to my parents:

Daddy – this should please you – I have bought some needles and wool and am going, after a disastrous attempt on my own, for a knitting lesson to Birgitta's this afternoon. I always remember you telling me that I should find something to do – like knitting or embroidery. I wonder what inspired you – what behaviour of mine, rather, inspired you to make such a suggestion. Well we all change in our old and wise age.

My father made that suggestion when I was 18, working in a bank as a secretary, a job I found incredibly boring. I sometimes went out dancing in the evenings returning home around 6:00 on the first train. On one or two occasions I bumped into my father who was always an early riser. On one such early morning encounter, he was amazed that I was up so early and then peering at me closer, he realized that I hadn't yet been to bed. He told me I was "burning

the candle at both ends” and hoped that I would find an occupation to fill my evening hours without having to go out dancing.

And a few weeks later I wrote:

Birgitta's knitting lesson has produced one Xmas stocking, but I doubt that I will get lots done. I could do one a year, but I think I would prefer to make sweaters. I've finished my patchwork duvet cover for the baby's bed and have started another one with sheep on the front. It's machine done patchwork – not as precise and nice as your's. Could you send me a photocopy of the Bernina fitted sheets explanation as Bernina Shop here doesn't have the magazine and is generally unhelpful. It's a Swiss German woman who runs the shop. Typical. Nei, nei das gits nöd²¹. ”

Edward's christening

I still had some things to plan and organize and one of them was Edward's christening. I wrote to my parents:

“The christening is planned for Sunday, Feb. 3rd at 2/3 pm. Marius is second god-father cause canon law does not allow Richard to be sole god-father. Zarina will stand in for Charlotte. So we have a real mixture of godparents. Marius is over the moon and is looking for a woman so he, too, can have a baby. Typically Swiss! Don't worry, I've bought myself a new outfit for the day. John hasn't seen it yet cause I haven't unpacked! What a good excuse!”

My sister had agreed to be god-mother to Edward. In response to my letter asking her, she wrote to me on November 24th, 1984:

Yes I would be delighted to be Godmother. However at the risk of offending or being misunderstood I want to tell you how I feel about religion – especially as it seems to be a concern for you. It's not easy for me to explain my feelings about my own spirituality because I'm developing them. I have been dealing with the issues of death recently have therefore come to deal with all of those issues concerning life, birth, death and the kind of meaning one makes in one's life and of one's life – by this I do not mean materialistic success but a quality of life as a human being – a spirituality. For me this doesn't include the dogma

²¹ Swiss-German for «No, no, that doesn't exist» which we found to be a typical reaction when we asked salespeople in shops for things that we could find either in the UK or in the US.

of the Catholic church – I just can't accept it. It doesn't feel right within me. I wish I could because organized religion is a comfort at times when there are no explanations – like death. My spirituality is a conglomeration of what I feel I can accept and believe and what helps me explain joy, pain, grief and wonder. Thus I think I can say I am a very religious person and therefore respect those who chose to worship or practice their faith within the confines of an organized church. Thus I have no difficulty at all being part of a baptism ceremony in your church. However if you are really looking for a Godmother in the traditional sense then my difference of beliefs and being 4000 miles away won't be much good to you.

So I'm throwing the decision back into your ball park! If you can accept me for who I am – then it's a deal – except – I'll only have your kids if you have mine!!!! Lots of love to you both and young Emily or Edward, Charlotte and Steve

In 1987, I started a book for Edward about his life. I wrote:

When we thought of your name, Edward, we were also thinking of others whom we love and who were also Edward.

There's my grandfather, Granny Lindley's father) who was called Joseph Edward Nuttgens, but who was known as Eddie.

There's Daddy's grandfather (Granny Betty's father) who was known as Ted, but whose real name was Edward.

There's Daddy's father, your Bon papa, whose name is Paul Emil Edouard. (If you had been a girl, we would have called you Emily).

Your second name is Jonathan, which was close to John in sound.

My mother's step-mother, Daphne, was so pleased we had named our son, Edward. She wrote to us on January 12th, 1985:

Many congratulations on the birth of your son, Edward Jonathan. Anne²² tells me that he is a fine baby and everything is going very well. If he does like to make a noise at times well he gets it from his great-granddad.

²² Anne is my mother's name. She lost her mother, Kathleen, after whom I am named, when she was six years old. Eddie, her father, and Kathleen had four children, my mother being the youngest. Eddie married Daphne when she was ten years old. They had eight children. Today I have 48 first cousins.

Eddie has 41 grandchildren and six great-grandchildren, 25 of whom are boys but this is the first one that is called after him – and I think Edward is a very nice name. A pity he never knew his great-grandfather. I am sure they would have been great friends.

It was the only letter I received from Daphne. In 1991 at my mother's 60th birthday, she took me by the arm and pointed to Edward, and told me proudly that he was named after her husband.

In Edward's book I wrote:

You were baptized in February 1987 (03.02.1987) by Richard Frost. You were seven weeks old. You wore Granddad Lindley's christening robe. We forgot to buy a white candle, and the church didn't have any, so Birgitta brought one. Granny Betty²³ and Hubert²⁴ stayed with us that weekend. Birgitta, Bernhard and Gaby came. So did Marius, but he left for Palau straight away after mass. Zarina was your proxy-godmother because Auntie Charlotte couldn't come. Afterwards we had lunch at home. We had a buffet de crudités, rognanade de veau, and we had the last layer of Mummy and Daddy's wedding cake for dessert with lemon and orange cream. And we drank lots of champagne that Christoph Kull had given us. Hubert gave you a spoonful of champagne which you spat out.

I wrote to my parents on February 3rd, 1985:

It's over: Edward Jonathan is baptized, champagne-feted and spoilt. Meanwhile we all stuffed ourselves on paté, salads, rolled veal stuffed with kidneys, pommes gratinées, lemon and orange mousses AND Mummy's wedding cake. Hubert is in ecstasy over your cake. I don't know how the ceremony really went. I guess it's like getting married. You're so emotionally involved that you don't take it all in. At least he didn't

²³ John's mother, Betty, who went to live in Brussels with her aunt at the age of 16 to learn French. During the second world war she was interned in a prisoner of war camp in Vittel, France.

²⁴ Betty's first cousin, Hubert. Hubert was 12 when Betty came to live in Brussels with his family.

fart, cry or burp. Of course he wore THE gown²⁵ and looked beautiful in spite of the dummy in his mouth.

I felt very much like you, Mum, cause I was up at 7:00 rushing around, cooking and cleaning, pushing people in and out of the bathroom, doing everything myself. And to top it, I had my bath 10 minutes before leaving in two minutes flat. I am my mother's daughter.

In the same letter, I wrote:

Hope you like the pictures enclosed. We have got his birth registered and his name in our passports. We did very well with his name: it turns out that Paul's third name is Edouard and Betty's father was Edward James. Can't do better than that, can you?

He's so changed and his personality makes me feel he's no longer a baby. He's nearly ten pounds too! I find it strange to be loved (so much) for apparently doing nothing. I haven't earned this love, apart from carrying him 9 months. I hand him around and let everyone hold him. He seems happy to be with others and he loves to look at people. When I come around, his eyes fix on me and his mouth starts working. I'm still nursing. No more bottles, but have to start weaning him in time to go back to work on March 1st. Have got a place in the crèche next to the hotel, bang next door. Am so happy about that, I will race through my work to get round to pick him up. Feels strange to have to go back. I'm losing my enthusiasm. Not that I'm dying to stay at home forever.

So the big question is when's the next one? I saw my doctor 2 weeks ago and he said I could start again. I would really like a summer baby next time so we'll have to wait. Then I will be able to give up working full-time, at least, and will be able to look after the family. Is this too much planning again? Didn't I learn my lesson the past time? It seems silly to stop work and look after one alone when we could have two, doesn't it?

Oh happy me: Monday last was a wonderful day. We sold the motorbike ..., found the crèche and bought a Passat station wagon. Yes, a family car. We'll have to fill it. ... This Monday we're going to look at a flat with a reasonable rent. I can't believe our luck these past weeks – things have changed so radically since Edward has been with us – or maybe we have changed our outlook and so influenced the environment around us.

²⁵ The baptismal gown belonging to my grandparents

Am reading a book called "Between ourselves, letters between mothers and daughters", edited by K. Payne. It seemed really interesting in the beginning with letters of Queen Victoria, Florence Nightingale, Susan B. Anthony, Amelia Earhart and others, but it has become increasingly morbid. Subjects of incest, lesbianism and divorce. How to tell your mother your stepfather slept with you? That you're a lesbian? That you hate her for divorcing your father? What a lot of emotional blah-blah it seems. Now I'm on the end chapter which talks about going through the separation to become an autonomous adult and free woman. It seems that until a woman identifies with her mother, instead of rejecting her ways of being and living (she has not separated from her mother).. So I suppose I'm "separated" because I find it nice to be like you. I don't know if nice is the word, but it amuses me to see your ways coming out in me. Somebody asked us whether we'd read all the child-raising and psychology books to prepare us for Edward's education. I will probably use all the methods used by my mother whether I realize it or not, and I'm sure I'll succeed, hopefully, as well as you did. It really means a lot to be able to refer to you and I can imagine it must have been hard for you without having your own mother's example. Reading this book I wondered whether I was ready to have a daughter and then I thought why get worried with all this cods waddle. At first I was pleased with the book and wanted to send you a copy. It's not my style to be wildly analytical, is it? Anyway, I wish you were closer so that I could call you up and boast about my little man – I hope we'll get a much bigger place so you'll be able to come and stay in comfort.

In the same letter, I wrote the following day:

Why did I say I wanted to boast about my son? He woke up at 4 a.m. and didn't want to go back to sleep. As he's sleeping in our room for a couple of days it was slightly annoying. So the sin of sins – I took him to bed with me at 6:30 and finally got to sleep.

I've just finished nursing him and stay in the quiet of our room and I can hear Hubert and Betty talking at the same time, non-stop, and John trying to get his bit in. I find it so tiring. I asked Hubert how he takes it and why does he always rise when she baits him? So he told me that he loves to get rid of his energy in a good, if admittedly stupid, argument. She says you have to say what you feel, even argue, because she never had a cross word with Paul and look what happened. I must admit that Betty is easier to take with Hubert around cause she can get spiteful with him instead of with me. She keeps on telling Edward that he's got a terrible mother and yesterday she slapped me because I picked

him up by the arms. After 3 days it's hard to take. On the other hand I've been giving her Edward as much as possible so she won't feel I'm holding him away. Did I tell you I went to a discussion group in the parish? We read and discussed "Laborem Exercens" (Of Human Work) written by JP II. He may be a wonderful man, but his views on women are influenced more by Paul than Jesus. Motherhood is Woman's Role (hard to imagine fathers giving birth), but in spite of me being over the moon at being a mother, I feel he has yet to realize that 1) it's not the only one for a woman and 2) he excludes all thought that men might be happy to take on more "woman" tasks if society allowed them. I can't imagine that the world will continue as it is now – economically and society structured in this so dividing manner (woman vs man role) and what bugged me in Laborem Exercens was that the Pope seemed to be as "with it" as Ronald Reagan exulting in yesterdays values. I think we'll end up with Latin masses. Richard smiles at me when I go on about feminism but assures me I am right to voice my opinion on such issues.

In my notebook, I wrote:

21.01. Visit Dr. B.

Bleeding stopped in 9th week

Breastfeeding stopped with Parlodel 8th week

On February 16th, 1985, I wrote to my parents:

We saw the pediatrician on Tuesday. We have another 4 weeks together, instead of one. She's given me an extra 3 weeks off to get my little boy into a rhythm and to breastfeed a little longer. Don't know if that is possible because the gyni's medicine was pretty radical. Apparently one should never stop so quickly. Dr. B. is a bit of a bugger not to have advised me better. Too bad, it's done!

Still – Edward got constipated and then developed a fever. So out of the freezer came mother's milk in plastic bags and he's much better now. On Tuesday or Wednesday I was so fed up I could have got on the plane for JFK! Instead I called Meroulla and Mark (don't tell John!) and had a "restorative" chat. Mark gave me some insight into a new father's feelings and attitudes which helped me because I was feeling that John wasn't being supportive. He's not having an easy time at work either. ...So he worries and worries about his job, about baby and me, about a flat, car, boat, etc. Must be hard being married to me!

I didn't get my extra 3 weeks off cause I found out I only had 6 weeks paid after the birth, not ten as everyone thought. Anyway, Dr. B. gave me a sick leave certificate for the 4 weeks I'd taken. So Edward went to the crèche ... and he loves it and everybody loves him. This week we had the flu (all 3) so we stayed home and looked after each other. I wish he'd sleep through the night. Luke does, so Mark tells us. You can't have it all. So I'm tired at work and of work.

I wrote in Edward's book:

When you were ten weeks old, I went back to work and I took you to the Creche Carfagni in the Paquis area. There were two girls, Sylvaine and Maria, who looked after you. You had your own bed with the toy Charlotte had sent you across the top.

Sylvaine put on a funny high-pitched voice to talk to you and it made you smile and laugh. Sometimes I would imitate her and you would smile for me. She would say, "Qui fait des jolies risettes²⁶?"

The first I took you I was so amazed that I wasn't with you during the day. I went from the Creche to the hotel and the first person I saw was Mr. Reber, the concierge, who asked me what I was doing, where was my baby. So I told him that I was coming back to work and that you were with Sylvaine. He told me off for leaving you. (Easy for him to say, but not easy for me to hear.). Then I went up to the office and it hit me that we weren't together and I started to cry, and my colleague, Mrs. Couvas, put her hand on my arm. Then she proceeded to burst into tears.

My letter to my parents of February 16, 1985, also mentioned my first day back at work:

Mrs. Couvas, who had her baby 3 weeks before E, spent 3 weeks back at work crying her eyes out. When she saw me back (we're sharing the office again) and upset on the first day E went to the crèche she cried more than I did. Then she went to see Felli²⁷ and resigned. Since then we have talked a lot about being a working mother versus mother/wife at home. She's looking forward to getting out of Hilton, but she's not sure the best solution is staying at home 100%. If I was happier in my job, i.e. if Lendi²⁸ left, I'd be on top of the world. So I'm

²⁶ Who makes such a pretty smile ?

²⁷ The general manager of the hotel

²⁸ The personnel manager and my colleague

answering ads in the newspapers for jobs elsewhere. Not for secretarial jobs though. I wouldn't jump from one hell to another.

Edward has taught himself how to suck his thumb – only he keeps pushing it down his throat too far and ends up gagging.

My friend, Françoise, has got herself pregnant by her 50 yr old married boyfriend. John and I spent lunch with her yesterday telling her why she should keep it. I wouldn't want to be a single mum. It's bad enough being a mum!!!!

Birgitta's already dreaming of her second. Dr. C., my normal doctor, saw us on Monday for the flu. I asked if I should start jogging or aerobics again and he was quite horrified. So – swimming 3x a week for 6 weeks, then jogging (or aerobics) 3 a week, and then a diet if I still have these extra 5 kilos to lose. But no diet until Edward lets me sleep 8 hours a night and no aerobics unless I want to collapse. And no ... planning a second baby until Edward is a year old and am in good shape. Edward thinks this is wonderful news and laughs his head off. He had a bowl of carrots and milk yesterday and ate it all down in ten minutes. A gourmand! Why do we have children? Great debate with Françoise – are our instincts in our deep, deep sub-conscious? Ask Dr. C.G. M.²⁹ next time you see him.

²⁹ Steve, my brother-in-law, is a Jungian depth psychologist. C.G. refers to Carl G. Jung.

B. Chapter 2: An interlude – some historical context

Where did I come from?

I am the youngest of four children, born in July, 1957. My parents, Anne and Christopher, were married in February 1952. Charlotte, my sister, was born in May, 1953. My brother, Matthew, was born in June, 1954, and my second brother, Mark, was born in September, 1955.

My parents emigrated to the United States, with us, in August 1965 and we lived in northern New Jersey for 18 months. My father worked for an American company in the insecticides and pesticides division as a technical specialist of insects and crops. In February 1967 the company decided it was best for his work for him to be based in Zurich, Switzerland. We attended the Intercommunity School of Zurich until we reached the age of 13, after seventh grade, when we were sent to boarding school in England. There was an American High School in the area, but my father wanted us to have English educations and go to university in the UK.

Recently my father said that it was the result of his career changes, that we now live very separate lives. Charlotte, a ceramist, lives in Philadelphia with her husband Steve. They have three children, Esther, Lydia and William. Matthew lives in Cheshire, England, with his wife, Sue, and their daughter, Rebecca. Mark and his wife, Meroulla, live in Cambridge, England, and have two sons, Christopher and Luke. Christopher is the eldest of the grandchildren. Luke is five days older than Edward.

My education

I was sent to a Catholic boarding school in England in 1970 when I was 13. I was very unhappy at being separated from my parents and very resistant to the nuns' education. In the last term of the school year, the headmistress told my father it would be best if I returned home to live with my parents. During this time, my uncle David wrote to me :

It was good to get your letter which gives much cause to ponder who will eventually win. Kate or St. Maurs? If I was a betting chap I think I would say it is now about an even money chance that St. Maurs will remain in existence rather than experience a similar fate to St. Trinians which, you may recollect,

was eventually blown up by the inmates! If you are considering a gun powder plot, do not consult your scientifically inclined brother because his efforts to make explosives at Castle Rising in 1969 failed dismally – for which failure I shall be eternally grateful!

I feel appropriately honoured because you did remember to send that first letter and so I have had two. The second had the additional news of your return to Schweizer schooling, which no doubt delights you. I suppose you will have few regrets at leaving St. Maurs Reform School!

Meanwhile stick out the last few weeks – don't break the place apart before you leave – someone else may want it!

I returned home and attended Swiss-German school. For a year and a half I was at a private highschool, a Gymnasium, and in 1973 I transferred to a private commercial school where I did a two-year diploma course in commercial and business management. I graduated in spring, 1975. I worked for ten months in a Swiss bank as a secretary whilst living at home. From 1976 to 1979 I attended hotel management school in Lausanne. I worked in Lausanne until April 1980 as a secretary – also because I had to resit my final marketing exam at the school. I started work at the Hilton in Geneva at the end of April, 1980, and was initially in charge of the reservations department. In the summer I was asked to take on the position of training supervisor.

Looking for my prince

My father regularly jokes with my daughter about me. It usually starts along the line of, “You know, Bea, when I see your mother and how independent she is, I often think back to when she was about 19 and she was dying to get married.”

On one occasion he added that I had taken the first man who would have me, which wasn't terribly flattering to John, Bea's father. The last time he started the story – in June 2011 – I told him that we had heard it already before, and even told the story in his place.

In the letters I received from various friends and family members, the topic was openly talked about.

A Catholic priest and friend, Father Peter, wrote to me on April 21, 1978 :

It is not bad that you are realizing what your own religious needs are and that they might be different from others. A period of searching, testing and possibly disappointment. It seems good to me that you can recognize this as your “religion” and that not going to mass in a way other than mortal sin of

religious neglect. I think not going to mass can be a very religious thing, and more painful than compulsive adherence to whatever it is that makes 2 people do what has always been done.

It seems that you are still looking for the soul-mate of the century and I encourage you in this. I would just remind you that there is no perfect man as there is no perfect woman. One must decide and the thing that makes the process possible is the little thing called love and that, after fifty years, makes marriage a viable human experience. There are practical things to consider too, of course, but love and human relationships are not in a way practical, unfortunately.

That spring I started dating Ray who was also at the hotel management school. He gave me a very expensive watch as a present and I told my parents about it. My parents had been planning to give me a watch as a 21st birthday present. Ray talked about this gift as if it was an engagement gift. My father wrote to me on June 10, 1978 :

Please come and see us either next weekend or the one after as we have to discuss you and things like birthdays. I courted your Mama from mid-September until Dec 31 before proposing to her = 15 weeks. Not the 6 weeks you referred to!

In the autumn of 1978, I went to London to do a three-month internship. During that time, my father was taken to hospital with a herniated disc, and had an operation. I came over from London to visit him, and he wrote to me on October 3, 1978 :

Dearest Kate, It already seems like a dream that you were home. I really appreciate your coming to see me so often in hospital and for the chance to say a few words from my heart. We have always had a "fighting" relationship but I love you dearly just as I know that you love me.

During my visit I told my father that I wanted to live with Ray when I returned to school in November. My father talked to me about the difficulty of living with someone from another culture, and that although we were both Catholics, he wanted me to live with him to make sure we were compatible. He said that it was a good thing that Charlotte had lived with Steve before getting married. He also wrote about the hotel management school that I was attending:

What a terrible place we let you go to, but somehow I kinda feel you can handle most situations. Never forget we are always around if your world temporarily seems to have fallen apart.

My mother sent a separate letter with my father's letter. She wrote :

Being in love is very difficult at times, at times it's heaven. Rather like being married. These last weeks have been very difficult for Daddy and I. One never really knows how each person is going to react to pain – or how the one who watches is going to react either. Hospital is such an unnatural place to be – and it is so good to have Daddy home and to be able to look after one another and feel secure again. So please forgive me if I complained and was difficult. I love your father so very much and he loves me and what ever the bumps we'll come through together, even if the boat looks a little rocky to the observers at times. That's life, my pet, and it will never be otherwise.

In December, my father was back in hospital for yet another operation. From his hospital bed he wrote to Ray and me on December 2:

Dear Kate and Ray,

The question of Kate doing the 4th course in February is to be decided by you two – I will find the money. You have to agree and accept the 5 month separation and there must be no chickening-out or emotional blackmail by Ray that he is lonely in New York or Hong Kong and cannot live a minute longer without Kate by his side. If he cannot make that promise then Kate would be foolish to start the course. If Ray really loves you, Kate, he will make the sacrifice – it won't be easy but many have done this before (e.g. I was 5 months in California when Kate was born). Pardon my bluntness but I'm a great believer in calling a spade a spade. Kate has a mind of her own and will never be a sophisticated lady, accept her for what she is, weird, eccentric, crazy, up one minute, down the next, someone who will never cease to surprise you but at the same time never bore you. If you can't, then she's not your woman, Ray.

My father used more or less the same words to describe me in his speech at my wedding to John in April 1982.

In January 1979 Ray left for his job in New York and I did my 4th year at the hotel management school. Our relationship did not withstand the separation and I wrote to him early July, instead of studying for my marketing exam, and told him I no longer wanted to come to New York to be with him. Instead I went off

to the south of France for the summer with Jean-Marc. I ended that relationship in the beginning of January, 1980, and my father wrote to me on January 18th : *Jean-Marc is an arsehole if he thinks you're a maniac depressive and you can quote me! You just have to sort and decide on your priorities in life which I hope will include your faith and then get on with living. Mr. Right will come into your life one of these days, quicker probably if you don't go on a hectic hut for him!*

Then there was another boyfriend, Eric. My sister wrote to me on October 6th, 1980:

Hi to Eric – if it is still Eric I'm sorry I'm not supposed to say those things. I think I envy you sometimes. Men can be boring.

And my brother Mark who had been married since May wrote to me on October 13th, 1980:

Remember that when Mr. Right arrives take time to sort yourselves out before you get to playing happy families. Marriage is one hell of a lot more complicated than just living with someone, but the good bit is it is much more fun.

By the time that letter arrived, I had fallen in love with John, a married man, and a colleague at the hotel. We met in the Geneva Hilton in the spring of 1980, just after the hotel opened. In charge of the reservations department I remember seeing two reservations for two Hilton employees, beneficiaries of employee discount, both with the same surname. John's father, Paul, was the financial director of Brussels Hilton. John was Banqueting Manager at the London Kensington Hilton after working his way up in the restaurants in Brussels, and then Paris. Several weeks later, I saw that John had a long-term reservation at the Geneva Hilton. He had been asked to put on hold his transfer to Brazil and assist the Food & Beverage Manager at the Geneva Hilton.

After I was nominated Training Supervisor, I was told to focus all training efforts on the Food & Beverage department, and to work closely with John to put in place all the training tools and practices. It was during this time that we got to know each other. He was married to Jeannette whom he subsequently divorced. Our relationship caused a great deal of talk in the hotel and within the company. We were married in April, 1982, in England.

B. Chapter 3: The dutiful wife from 1984 to 1988

In my letters to my parents before the birth of Edward, I often wrote about John. The main subject is John's career opportunities. He had worked for many years for Hilton and was expected to continue to move from one hotel to another, each time being promoted. Being with me, and being in Geneva put a brake on his mobility.

Letter dated October 15, 1984:

I'm on my own while my hubby is spending the afternoon in England for an interview. I dropped him off at 11:00 and thought I should check he'd got on and found that the flight had been cancelled. So I took him to Birgitta's for lunch and Bernhard joined us too. So much for my well-planned day off! Anyway he should have left at 4 and will be back at 9:00! The hotel is near Gatwick. In 2 wks time we're going to Torquay for an interview – if I'm allowed to travel. We're officially on the moving list and Liz Windsor called us last Thursday to say something interesting is coming up in England. In spite of all these other interviews I think John would really like the job of F&B Manager in the Park Lane establishment. It looks like the ball is really rolling ... I went to the renters' association who are ready to take Viktor to court for me because the contract is illegal. They're a bit red. Anyway I did find out that he has no right to raise the rent – if anything he should lower it!!! He won't be happy when he finds out about that. Now John is finally sleeping calmly.

Letter to my parents dated October 29, 1984 :

John turned down the first job he was offered in Copthorne, near Crawley. He said the guy's watch was so shoddy that obviously the man had no self-respect. Then after a week the man called him up and asked him if he was REALLY interested. So he said, when you make me an offer I would like to compare it with the other hotels and Hiltons offers and I will make my decision. Then Profile, the headhunter agency, calls up and says that Copthorne asked them to call John up and find out if he's REALLY interested. So John said why can't they make an offer just like that? I guess if they feel he's really interested the salary would be lower than if he's not dying for the job. Sounds almost like Hilton tactics. We had a movers company in for an estimate: it would cost about

6'000.- to move everything back to England (depending on who did the packing we could make it cheaper). So that can be used for negotiations too.

John sold the BMW yesterday because he got a very good offer so we are now back to being a one-car family. I guess I'd better get used to it, because if we go back to England we'll only be able to afford one car. However the boat will be paid off by Xmas – hopefully so that is a relief.

Letter to my parents dated November 26, 1984:

The latest crisis is John's in plaster with a strained Achilles tendon from running. So I'm driving myself and him to hospital and getting a double room. He went running on Friday and after 12 kms it started hurting. Luckily he was almost home and I took him to the doctor's straight away. I take him back to the hospital on Thursday for a further check. It hasn't "gone" completely so there's a good chance that it will heal quickly, but no races for a while.

An extract from Mark Keith's letter dated December 17, 1984 :

Last month I wrote seriously a fine manuscript on John's expertise as a sailor. I went into great details about his prowess on the high seas and his unique skills with ropes and bonds. I mentioned too his physical fitness, his early morning run and his use of Michel Felli as a running mantra. I also referred to this hotel experience in a small way on the outside of the envelope. I strongly believe on the basis of my recommendation he will never have to worry about his career again. Seriously though, folks, IMP Hotel (run by dwarfs?) of Torkey did want a reference, does this mean you may be hoisting anchor?

Letter to my parents dated January 19, 1985 :

John is supposed to go for an interview with Inn on the Park on the 28th. Penta group are looking for an Operations Analyst at headquarters in Ascot and the Grosvenor want a F&B. so he might squeeze those in together. Or knowing him, he might not go at all. I don't know yet if I'm joining him.

We nearly got a Range Rover the other day. John saw a good deal on a second-hand one. Thank goodness, we'd just paid in the money for the boat!

Extract from a letter to my parents dated February 3, 1985:

John was supposed to have 2 weeks off, but his maitre d' of the Regine's³⁰ has typhoid from eating Spanish oysters, so he had to go in Friday night and last night, so he was a bit of a zombie.

Oh happy me: Monday last was a wonderful day. We sold the motorbike (only lost 400.-), found the crèche and bought a Passat station wagon. Yes, a family car. We'll have to fill it. Hubert has lent us 13'000 to pay him back over 2 years. That's super of him. This Monday we're going to look at a flat with a reasonable rent. I can't believe our luck these past weeks – things have changed so radically since Edward has been with us – or maybe we have changed our outlook and so influenced the environment around us.

John said very honestly that he's like her (his mother, Betty): money burns a hole in his and her pocket!! How to go easy – and buy 3 cars in a year!

An extract from my letter to my parents dated February 4, 1985 :

Mr. Kuhne, general manager at the Ramada hotel, called and invited John to lunch on Wednesday. Oh, I will miss him at the Hilton if he leaves. 5 years of working with him.

An extract from my letter to my parents dated February 16, 1985:

He's not having an easy time at work either. I told you he had another interview with Ramada. This time they talked seriously about the job, possibilities of the F&B operation, working together and John feels very strongly about taking it. The GM will call him at home before the end of Feb (12 days to go) to let him know when he could start. Now he's worried that it will fall through. The man also told him that since John has been in Regine's people have been talking about it, that it's taking over the Griffin's for the most popular discotheque (amongst Geneva's so-called high society) which is ego-boosting for John. In spite of that, he still loathes doing the job. Hilton will be hard pressed to find someone to replace him down in the dungeons.

Letter from my father to John on June 8, 1985:

Dear John, Kate called me a couple of days ago to tell me that Hilton has crapped on you again. I don't believe this has anything to do with your ability

³⁰ John was given the additional responsibility of running the Regine's nightclub in the Hilton complex

but has a lot to do with your nationality. I can objectively look at the Swiss now and I see a small-minded, chauvinistic, mean, hardworking, un-innovative, un-Christian bunch of people, enjoying (by some dubious and some indubious means) a very high standard of living and living in a scenically beautiful country. Also I have long since decided that if one is learning something in a job in which one is not happy, then stick to it, but get out it is doing nothing for you (except paying the bills).

My assessment of your situation at the Noga is that you are bored with / dislike the job, have learned all you can (or > 90%) and that because you are not Swiss will never make it higher. This, I repeat, has nothing to do with your ability. Promotion is often based in any organization on who you know, not what you know. This explains why I was crapped on by Cyanamid from 1968-1972 and was promoted in 1984.

You have two options, I guess.

Look around Geneva for a job which will challenge and teach you.

Look around elsewhere (including Hilton) for the same.

Don't do anything in a hurry (moral of frying pans/ fire is pertinent. Also grass over the fence always looks greener).

Talk to your wife (something husbands don't do well as I learned 15 years ago. Maintain your dignity and your morale by saying to yourself "Felli is a shit" but not to others.

Life is full of unfairness (Matthew's expression as a boy was "it's not fair") and prayer is about the only answer I know to that. The Christian religion is a great source of strength when one is in despair, feels resentful and aggrieved. One can grow from any experience if one gets oneself sorted out – that often requires help from someone like Father Richard.

This all sounds like a sermon but its not meant to be. I hope it helps. We are all very fearful of what others think of one. You are an OK son-in-law married to my difficult but delightful daughter and we are thinking of you both very much at this time of crisis.

With love to you both, Chris

PS This should not be answered but let us know what's happening.

An extract from my letter to my parents on June 11, 1985:

And so life goes on. I think John is starting to accept what has happened. I'm still ready to spit in Felli's face, but have been surprisingly strong about it – smiling at them, etc. Yesterday I got back into Welti's good books by doing one of Lendi's jobs, doing a survey on performance evaluation and writing up the

results. Today I will receive my five-year service award. I was really looking forward to the day when I got it, but today's ceremony means nothing, but I've managed to survive five years with a bunch of bastards. Felli is very worried now about the effects this whole story will have on department heads, so for the first time there will be a department head outing next week. What's different about this one, compared to the department head dinner in December? This time asst. department heads are not invited, neither are spouses. That is pretty understandable – who wants to look John in the face? They're all shitting bricks and quite assured that arse-licking is the way to get places. Anyway I have decided that I am not going, but will give an excuse on the day. I am not going out and leaving my husband behind and I don't care if what is said is negative about me.

John and I talked about the whole thing the other day and John says he will not take a decision until the end of June. Felli is dying to know what's going on and keeps repeating that he should go and talk things over with him before taking a decision. Today he should call back the head-hunter in England and put his name down on the list again. As I say, he's picking up again. He's also taking two sleeping pills a night so it's still very hard for him. I talked to Richard³¹ the other day about it and he gave me some good advice about how to deal with it, which I'm following and it's working. Hubert arrived yesterday, seeming to need to be with us, so John has his adopted-father to talk to. In all this, Paul has not called John, yet he was one of the first to know.

I talked to Liz Windsor, Spearman's assistant who is leaving on June 13, and she told me that in order for him to regain credibility he should put his name on the transfer list for anywhere in the world, as of September when he gets his C permit³², and accept the first thing they offer. As far as we are concerned, there should be no such pressure so that's why he's calling back the head-hunter. I think we should move, and move somewhere out of Europe, away from this area which we know so much about. For him professionally he has nothing more to learn in Europe. I'm not saying our bags are packed because we don't know what our next steps really will be, but I really would like to go now. I've written to Mark Keith as well and said that John would now consider Far East without telling John. Also I told Mark not to let on to John that I told him. Mark's pretty good about respecting a guy.

³¹ Richard Frost, a Catholic priest, close friend and Edward's godfather

³² The Swiss residence permit, similar to a US green card

Thank you for your support. We do both feel that this cloud has a silver lining somewhere. I think it's really time we did something: we have grown very complacent here. If we look back and see what we've built up here – both in our private lives emotionally and materially – I think we have to be honest and say we've done very well for ourselves. Anyway everything is still to be discovered and hopefully I'll be able to tell you more by the end of the month.

Thanks for your letter. John was very touched. He has put an ad in the paper for the boat. He also called the London-based head-hunter who already knew (!) and the guy has put him back on the interested list. He's very depressed again, saying everyone now knows he's a loser, a failure.

An extract from a letter to my parents on September 29, 1985:

Many thanks for the teapot. John has decided that it will go to Rabat with us. The formal offer came yesterday by post so I've just read it this morning. We get home leave once a year! Everything else is like we said. We'll have a suite with bedroom, living-room and a tower room, which I suppose, is the small bedroom for E. John is supposed to be down there by November 15 and he plans his last day at work to be November 1 here. However the new training supervisor (whoever he or she is) does not start until November 1. Mr. Felli still hasn't talked to me and his rating on my popularity scale goes down by 5% each day. In the meantime, Welti says I'm leaving with my husband, but staying to train this person.

John has a double tendinitis: the Achilles tendon and another small tendon stretching from knee to foot. He has finally stopped running, but it doesn't look like it's improving. He goes 3x a week to the physio and sees the doctor next Friday. He's gained 2 kilos and looks great! He's also got an inflamed ear drum and all the sympathy I can give.

By the way, my replacement, a psychologist, starts Monday in Brussels for hotel operation training for 3 weeks, under Roest's supervision. Then I will be with her from October 28- November 8 (minus one day for moving). We're flying out to Rabat on Sunday, November 18.

Off to Rabat! November 1985

From a letter to my parents (which I never sent) over a couple of days starting November 19, 1985:

I should be unpacking my suitcase and getting organized, but I'm so bushed after having breakfast with Edward in my arms ("Sorry, Madame, we do not

have a high chair”) that I just feel like lying down and sleeping, as is Edward. Naturally in a bed which is not deep enough and out of which he can easily fall (“I’ll look for another one, Madame.”) So here we are! At least I don’t have to contend with a day at work today. And there’s no urge to do any work either – nothing in training to do here, not with staff who’ve been here 18 years, who only leave on retirement or because they’re caught stealing.

We arrived at the airport of Casablanca yesterday 1 ½ hours early so we had to wait until the General Manager, Mr. Müller (from guess where?³³) came. We thought we’d been forgotten! The morning had been hectic cause we stayed at Birgitta and Bernhard’s, and they only have one bathroom, so we left with no time to spare to pick up Hubert (staying in some cruddy hotel) and our suitcases from the Noga. Hubert was asleep and took 10 minutes to get down – and I could have bitten his head off. So we made it to Cointrin by 9:10 with the plane leaving at 10:00. Not Lindley standards at all! 8 pieces of luggage, 96 kilos and we only had to pay 12 kilos overweight.

When we arrived at Casablanca we got pushed to the back of the queue at customs by somebody who knew somebody who would let his five friends in quickly. The officer took 5 minutes per passport – it must be union regulations. In the baggage hall our 8 pieces were no longer on the moving thing (conveyer belt), but had been placed on the floor as far away as possible from the exit door. A little guy was guarding the luggage and John asked him for a trolley. “Tu veux un chariot?” So he stamps over to the lift and then flaps his arms up and down and then comes back all apologetic – there aren’t any more trolleys. After standing for an hour outside afterwards, it was quite obvious that the only trolleys in the place had porters attached, and there were only 4 to be seen. So, anyway, we lugged our stuff plus hand luggage (a knapsack full of toys) over to the customs who took his time to first check all the Morroicans’ luggage, waving us to the side, before making John open up every other bag and then putting a chalk symbol on each piece. Our new luggage is now baptized. The white Samsonites were a problem – he had to find a red stick of chalk. After having our luggage then checked by another guard, who’d been watching us from two meters away, for the chalk mark, we were out to wait.

³³ I’m being sarcastic. Mr. Müller was Swiss-German.

Tuesday evening:

John came up from work and told me he was worried that I would be bored here. I can't think of anything else that I know of, in my frame of reference, that I'd rather be doing. I don't miss Switzerland and the Geneva lifestyle. Went down to the British Embassy to register and put down HOUSEWIFE under profession for the first time in my life. The girl seemed like she pitied me. It took me an hour to walk there. The doorman was sure I shouldn't go by foot. I didn't quite realize how far it actually was, and got a little anxious when I did start to get near it, and a young man started to walk next to me and talk to me. After a lot of head-shaking on my part, he gave up. Afterwards I'd obviously missed the hotel bus back and tried to get a taxi. That took me a good 20 minutes. People ride taxis in groups here. Met the General Manager's secretary who is married to a Moroccan university professor. She likes to chat.

A couple of days later:

I walked up and down Avenue Mohammed V through the chic shops. This is supposed to be the equivalent of the Bahnhofstrasse (in Zurich). It's a long way to come – to look for Pampers. I found a couple of baby shops and French clothes galore. People suggested I go into the medina (market) but I was too scared. Then I found a pharmacy with a French equivalent of Pampers. A big box of 26 cost 210 dirhams. I only had 100 dirhams on me, so I couldn't even buy the smaller box of 12 for 110 dirhams. Needless to say I felt a mixture of frustration and depression. So I went into the medina and found a bag of 20 for 78 dirhams. They don't soak up one pee and Edward is having regular changes of clothes as well as Pampers. The housekeeper came up for a chat. I met her when she came to the Noga for cross exposure training. She suggested that I get a full time girl to look after our apartment and Edward for the royal salary of 450 dirhams a month. That's 2 bags of Pampers!

So if I get terry cloth nappies and have a girl full-time who can wash them out, I'll save money! Finally the three dozen nappies you bought me for Edward's layette will come in use!

A packet from my sister-in-law, Meroulla, arrived with a letter dated November 28, 1985:

Thanks for the postcard. It was good to hear from Mum that you are settling down and that you are comfortable in Morocco. I hope the slippers enclosed will fit Edward. I actually bought them at Bromley Market for Luke but they are tiny for him. If they don't fit you can save them for his little brother or sister!!

(Edward's!). Luke is still trying to cut a tooth and so he tends to be quite "clingy". We wish you all the best for Rabat and maybe you could arrange for a belly dancer as a Christmas present for Mark!!

An extract from a letter from John on Thursday, December 5th, 1985 :

Your telex arrived on Wednesday. Useless to say I was worrying and was about to call. It is very lonely. I miss you both so much. The loneliness is even more acute in a place full of strangers.

I have given this letter to Mr. Müller who is passing by Zurich and will post it to you. It enclose the keys of the boot. The small one is for the padlocks, the goldy coloured one is for the main hatch and the wide one is for the engine. Jean has a double of the one for the hatch and the other doubles for the one in the chart table.

El Attar has been sick for three days, but is back now. Life has started to become stressed. I have had dinner with Mr. Denis, the French man, and will dine again with him this evening. He is very kind because he realizes I am a little bit sad all on my own.

It is really nice to know that you are both in our home and I can't wait to join you. Today I went to the pottery and bought 2 lampshades for our suite and 6 breakfast bowls which I hope to bring back completely. I will be leaving very early Tuesday morning and should arrive in Vienna in the afternoon. --- The flight back will normally arrive in Basel around 2 or 3 in the afternoon and the corresponding flight to Geneva is at 5. I thought I will probably take the train as this would mean being back home earlier. In any case I will call you from Vienna upon arrival and from Basel upon arrival.

Hoping all is well. I want you to know that I love you both with all my heart.
John

Edward's little sister was on her way

The pink book in which I recorded all the details about my first pregnancy came with me. It seems that I got pregnant almost as soon as we got to Rabat. I missed my period for the first time when I returned to Switzerland in December while John was at a Food & Beverage area meeting in Vienna. When I returned to Rabat, I asked one of the restaurant hostesses for the name of a gynecologist. I called for an appointment and the restaurant hostess accompanied me for the consultation. The waiting room was full of people, women accompanied by their husbands and children. Being used to finding one or maximum two people

before me in a doctor's waiting room I felt certain despair. It would take ages for my turn, and the restaurant hostess had to get back to work. However I was whisked in shortly after arriving, which turned my despair into guilt for having 'cut in front' of the others. What remains from that visit, is a piece of notepad paper where the doctor noted down various things that I cannot read. It does however say that my baby is due on August 18. The examination was very different from the ones I had been accustomed to in Geneva. There was no echography among other things.

My main concern was my lack of comfort at the idea of having a C-section in this country. John's assistant joined us one evening in the restaurant, saying his sister had been massacred. He was very upset. His sister had had a C-section. I tried to reassure him that C-sections were safe, but I found myself growing dizzy while telling my story and fainted, keeling over onto John's shoulder. It soon became obvious to everyone that I was pregnant, perhaps even before the restaurant hostess had told those around her. I had 'morning sickness' that lasted until the late afternoon. As we had all three meals in the restaurant each day, the staff often saw me walking quickly from the dining room to the restroom or rushing up to our apartment after breakfast or lunch.

An extract from a letter to my parents on January 8, 1986:

First of all, on behalf of my two men and myself, many thanks for all our presents: teddy bear, camera lens, fun outfit and sheets. They are all very appreciated (especially the fun outfit) and suit us right down to the ground. I already wrote you a letter but decided it was really too boring so shall try and do better this time.

Last Saturday John's assistant, El Attar, one of the most charming Moroccans I've met – took us shopping in the hotel's truck (a Renault 4 with faulty steering). John, Edward and I were in the back and John's future secretary, Jill (an English girl divorced from some Moroccan) in the front. We went to the pottery which consists of about 20 small individual potteries, each place making its own specialties. While El Attar and John haggled over prices Jill took me round and showed me 3 potteries. The kilns are a sight! I would have loved to go down and watch the workers, but wasn't really sure if it's the thing to do. Watching them do the hand-painting was incredible. Problem is you shouldn't show too much interest if you want to barter afterwards. John bought two lamps with matching hand-painted lampshades while I was away. This time we came away with a hanging macramé thingy with a pot which the gardener filled for

me. Behind the pottery is the wicker market with lots of Moses baskets. There too you can watch them making the stuff.

After that we went off to the carpet baggers in the Medina, rue des Consuls and bought 2 bedcovers for \$7 a piece for our sofas. Our suite is done in orange which is driving us mad. Then we made a couple of stops for hotel purchases, and John bought Edward his first proper chair, a little wicker armchair which Edward pulls up to the coffee table for his tea. And then we bought beignets (doughnut rings) and munched them on the way home. It was really a fun expedition. Jill, obviously, knows a lot of the ins and outs and I look forward to Feb. 1st when she starts here. She used to be Müller's³⁴ secretary and she left when she got her divorce to work for Spearman (whom she nearly left after a month). Then a friend here at Esso contacted her and offered her a job at a super salary (\$720 a month) and she came back and has fallen in love with another Moroccan (who got married on Saturday) who thinks he's the Clint Eastwood type. Anyway the job at Esso isn't too interesting and John has persuaded her to join his gang as "F&B administrative supervisor" for \$400.- a month. All this money means that John's earning an absolute fortune (\$2'000.- a month) even if 40% goes on taxes.

Müller, the GM, really likes John and is so pleased with his performance. We had dinner on New Years Eve with him and the GM of Air France and his wife. It was the most delightful New Years Eve John and I have had to date, even if I ripped my shoulder blade badly while dancing the rock'n roll with my hubby, which landed me in bed for 2 days. Anyway the whole menu (painted on plates) and service was super and Müller couldn't stop raving to me (in Schwyzertüütsch³⁵) about John. He told me that the GM in Tunis is really eating his hat because he didn't get John. Then we had a drink with him the other night and he talked of promoting John to Exec. Assistant Manager next year. The only thing is I don't know if John really wants to be here next year. His work is giving him a lot of satisfaction (depending on when you talk to him) but he misses his sailing, his running, the bread shop and seems to forget the pains of Geneva. I must say I do not mind being up in Lens at all, but I'm not saying anything because I don't want John to feel I'm not happy. I'm not unhappy

³⁴ Peter Müller, a Swiss national, was the General Manager of the hotel.

³⁵ Swiss German dialect

about anything in particular. I think we're hitting a patch of "hard times" settling down and coming to grips with what we have here. I'm not on top of the world with morning sickness galore which lasts until tea-time. I've gone off my food completely and last night we ate Vietnamese and I nearly had to leave the table. Finally my weight's going back down.

Edward has his own maid now to wash his shitty nappies! I should be starting work part-time soon and am staying around to help him adapt. He has fallen in love with me and runs after me, wants to be picked up and cuddled, and is really lots of fun. He's also playing more with John – and getting into trouble, turning his bottle of milk upside down, shouting, smashing the alarm clock, pouring tea over everyone. But he really is adorable – and one of the very good things about being here is being with him so much.

I plan to return to Geneva for a check-up in March (most probably early March for two weeks), depending on when M&M come out for a week. Apparently, March will be warm and April hot. I've checked my book for the expected date and it's August 18 which means I'll escape the heat as I would have to fly out by the 35th week.

John hopes that Betty will come and keep me company. I hope Birgitta will stay home instead of going to Sweden cause she now lives about 2 kms from the Clinique. John will come over, hopefully, in time for the birth and then take his annual vacation. Anyway we still have to get that far.

We had a golf lesson last Sunday and think we might for a couple of lessons a week. It's more interesting to play than to watch. The hotel is full of snobby German and Swiss tourists having a cheap holiday (a double room is about \$30 a night) and kicking up a stink because there's not enough bread on the breakfast buffet to make their lunch sandwiches to take on the golf course. One rather rich couple came to the hotels Xmas cocktail "mit viele Grüsse von Herrn Denny" They and another couple shocked the Moroccans by taking two bedrooms per couple. They think the Swiss are very strange not to sleep with their women, especially as they are so rich and could have any woman! Moroccan logic! There is quite a high rate of divorce here and lots of "loose" women – and men naturally not considered "loose" but normal! Edward is fighting the maid over lunch. When the weather warms up I want them outside all day.

Thanks very much for the phone call. Don't worry – I'm not unhappy. I'm just pregnant! Edward gives you a big kiss and cuddle and we all send you lots of love, Kate

A letter to my parents dated January 19, 1986:

Dear Mum and Dad,

It is 7:20 pm and both my men are in bed and there is peace around me. John was on duty today so he took half Friday and all day Saturday to go to Casablanca where we got a free room at the El Mansour hotel. The Chef came with us so it was partly business and all on expense account, and his girlfriend joined us on Friday evening. (Chef is married and has 5 kids and can't afford a second wife so has a girlfriend; they're both strict Muslims.) It was really super to get away from the hotel where John was going mad. We went shopping to buy ourselves some clothes and ended spending on Edward instead. He now has a smart pair of red Kickers, a blue and red anorak and a light pair of blue jean farmer pants. You can unzip the sleeves of the anorak which is very practical. Apart from that we ate and ate. We stopped on Friday for lunch in El Mohammedia and had Paella. In the evening we went to the Hyatt Regency and ate Italian. The Hyatt is very typically Hyatt in décor (with a Humphrey Bogart bar) but the restaurants aren't doing well. They're planning to expand and build tennis courts, swimming pool, etc. bang in the center of this polluted town. The ghettos are appalling and there's supposed to be a lot of pick pocketing, mugging by gangs and so on. The shops are all right but if you want good quality it's the same price as Geneva.

The surprise of the weekend came from the El Mansour's General Manager (ex-Lausanne school) who told us that Hyatt is definitely taking over the Rabat Hilton – in April 1986. And it's all very strange. [...] When we got back here we found a group of about ten persons from the Paris-based architect firm who did the original designs in September for Hyatt of Rabat.

Another Hilton mystery is now weighing heavily on my hubby's shoulders. He has been nervous about the future ever since we thought I was pregnant. Can you imagine what he'll be like if I have 4 as he wishes?

Tonight we are supposed to be having dinner with the owners of one of Geneva's most expensive restaurants, Parc des Eaux-Vives, Mr and Mrs. Perret. I went to school with their daughter, Sylvie. I say supposed to because I

don't know if John will surface. They know a lot of people and he's helped friends of Sylvie's to find job so we see how the conversation develops ... In any case I would still like to plan on having my Mummy to look after me in Lens this summer. If baby is due on August 18, I should leave Rabat by July 13. I shall be off to Geneva after Matt's stay (March 8-16) for my check-up and see what the doctor says. The morning sickness is really limiting itself to mornings – it's coupled with changing my son's shitty nappy (oh, I do miss Pampers.) I still can't eat a lot and usually if I have a starter I can't touch my main course. It seems that I'm looking thinner in the face.

Little boy's character has changed since he is "upwardly mobile". There's a whole new determination there which has me after him non-stop. This is the age of discipline, where NO is learned with stern faces and slapping of little hands. But there's also more affection – he runs to me with his arms up in the air. And he looks to John for his approval and wants to play with him. What a kid.

The following morning:

You have to drink like a fish to keep up with people like that (the Perrets). Thank goodness I have a good excuse.

And a day later:

It looks like we have made some good friends. They have promised to send us the Hotel Revue³⁶ and "if we hear of anything, we'll let you know". He firmly believes that after gathering experience with a hotel group you should take over a hotel and later run your own place. They are real hoteliers are commercially-minded people – not like Felli. They know people's names, give you the impression they are really interested in you and in the world around them. John has been approached by an old French gentleman living in the hotel and with whom we have dinner very often to join the Freemasons, and has given him a couple of booklets. He says it is recognized by the R.C. Church. When I see the photos of these old farts with their silly hats and decorations on, it sends the shivers up and down my spine. I think we have enough symbolism with Catholicism. I shall have to write to Richard for his input. I gather women are excluded.

³⁶ Weekly newspaper of the Swiss Hotel Association

We're planning our next weekend off in Fes. The chef is raring to go – so he can take his bird again, I suppose. Apparently you're taken back to the 15th century and find in the medina butcher, baker, candlestick maker – all the trades are there.

I went with the Perrets yesterday for a quick tour around Rabat with a guide to see some of the “interesting” things. The most interesting was the guide who told us that the king had four wives and 150 concubines, and he could only afford 2 wives, to which old Perret replied he could only afford one! But I have to admit that we saw a couple of worthwhile things even if he made us wander through the medina here which is all right the first time but “when you've seen one, you've seen 'em all”.

The Moroccan nanny didn't last long. Two days and gone! John couldn't stand her, Edward cried all day because she kept on picking up his toys and putting them away and wouldn't play with him, and I was feeling rotten with a cold and couldn't take all the complaints. Anyway I saw the GM and told him I was pregnant and seeing I felt so sick I couldn't keep to a schedule. So I will work unofficially for John. It was just as well I saw him because two days later, with the Training Coordinator, a French bitch, he asked the Personnel & Training Manager to resign. And I don't want anybody to feel that I pushed the guy out. I'm not like Alan B. I don't get an ego trip out of power!

I've just finished putting together the F&B project for 1986 which my husband delegated first to his assistant and then to me. He says I've done it so efficiently he's going to invite me for supper in the Grill downstairs (where we go every evening). The last of the Big Spenders!

Edward is in the process of breaking something next door so I'll finish now and get this in the post.

An extract from a letter from my Aunt Hennie dated February 19, 1986:
I am glad you are able to meet people. This makes all the difference to life and that you are seeing a little bit of the country at weekends. You know what they say about “All work and no play ...!” I am not altogether convinced that a high standard of living is a recipe for happiness. It seems to me that people, family and friends, play a bigger part, but I guess each one of us has to find the good road for themselves. For me, I think, it has been finding a faith and purpose in life which not only spilled over in an interesting job, but in all sorts of other ways, like the Union work. I find that although God has work for us all to do,

He always puts us in touch with people, some of whom become our lifelong friends. This is what made my birthday party such a memorable one – old friends and family together.

I do hope you are keeping fit. How convenient of you and Charlotte to produce at the same time – your poor Mother doesn't know which way to turn! But apart from that I am delighted for you both. Just make sure that one of you produces a girl!!!! Much love to all of you.

An extract from a letter from John dated February 2, 1986:

The sun is visible, it has stopped raining, the wind has dropped and apart from the very deep sadness of my heart, the whole thing looks just a boring ...

I gave in my written resignation on Wednesday. Since then the full power of manipulation of the company has set forth, the five week battle is on. For the first time since joining the company I feel free and responsible for myself which is a definite advantage. The prospect of being unemployed is rather worrying however there is a price to pay for this type of move. Hilton International people are so vain, it is just unbelievable. You could never imagine the level of absurdities I have heard this last week. As usual the game is to try and ride on their image, all the wonderful things you could lose (which cannot be put in writing for obvious reasons, but will obviously be yours if you are patient and smile), the most wonderful working conditions and the nasty outside world for which nobody in the company is prepared. This nasty outside world bit seems to be the turning point of their problem, since that's where the guests come from and that's where I am going.

Suddenly I was supposed to be fully aware of the potentially unstable situation of the hotel before I came and I am the big baddy because I am leaving them on the spot. I wonder what would have happened if I had not been up to par – would they have been 'badies' for getting rid of me? No, that would have been business and I should have looked at my contract better.

The question of you coming back has risen a few times, obviously it would be easier to work on you as well as me. So my answer has been no. Life has fortunately trained me for these circumstances, no sentiment and a lot of determination helped by the solidity of our family bonds will see me through. By hiring a relative of the man who should sign our paper for the money transfer, I got all the required documents to the bank, made the transfer for January and will make the second transfer in March with my last pay, only to find out that no foreign currency has been made available for this type of

transfer since December, they do not know when it will be possible. Absolutely no comment possible on that one.

I called your lady friend and booked my return flight for Thursday, 27th March, this means we can spend Easter together. It was important to book as traffic over that weekend is supposed to be heavy.

Next week I will try and send by post Edward's chair and car.

I have been working hard, have dictated a good bit of my hand-over notes so that I keep my mind busy. Times of separation like this are terrific reflection opportunities which bring out the full strength of a relationship. It is wonderful to be so far apart in so much duress and feel the glowing warmth of your love and the tight material of our relationship. I miss you and Edward for the lost time of happiness we could spend together, but I hold you close to my heart.

John

Extract from a letter from my mother, undated, early February, 1986:

This must all be very unsettling to you, but perhaps by now you know more about your future. So hard to put ones faith in the Lord at these times, but there does seem to be something round the corner if we have faith. I hope something comes of your contact with the Perrets.

I presume by now you have heard from Charlotte – isn't that the surprise of the year? How could you two sisters plan on babies in the same month and the same week? It puts Gran in a bit of a dilemma – but I'm still planning on coming out to Lens to keep you company...

Dad and I are very excited for you both... It all seems to be happening now in a rush. So I'll plan to be with you in end of July –August and we'll look forward to Bundnerfleisch picnics in the mountains and sipping white Valais wine on your balcony in the evenings while Edward sleeps, exhausted from dragging Granny up the hills. Yes I am looking forward to coming. ...

Yesterday we had about 6 inches of snow. As it was forecast on Thursday, Dad brought his work home so he could work all day. Such a "Theater" every time a little snow falls. He could have easily gone to work. We're off next weekend to Philly to spend our wedding anniversary. God knows how many years and I still haven't had a sabbatical.

An undated letter from John written in March 1987 from Rabat, Morocco :

The king decided to give 5 days public holiday starting today on the occasion of the 25th anniversary celebrating his coming to power. Yesterday evening I watched him on television waving from his car as it sped though St.s lined with

the masses waving little red flags. The sun was shining – he looked like an animated doll, his arms going up and down amidst the formidable motorcade. For a moment, I could believe in his gleaming smile, he owes so much to those crowds. And that's the news.

Yesterday I sent two parcels with Edward's car and his chair. I put in the 2 covers, I hope I filled in everything properly. It only cost 180 dirhams which did not seem a lot. I received your express letter, so you know I had already handed in a hand-written letter. I wrote a letter to my father this morning so that he gets our side of the story. My salary came in yesterday, 1420 DH had been taken off for our telephone bill. Mr. Mueller agreed to have the customer surcharge taken off only with the telephone system, it is not a lot.

I have taken up swimming in the afternoon, 25 laps, as well as running the usual 12 kms in the morning. It is doing my back some good, keeps me busy. The sun appears from time to time and the wind is still strong. I understand that most of Europe is going through a cold spell. Has there been the 7 meters of snow as expected?

Pressure has subdued from Mueller. He is a crafty fellow and uses humour and little timed remarks instead, to which I am refraining to put cynicism as an answer.

We have got to get our act together not to put ourselves in situations like this anymore.

I miss you and Edward so much, total sadness fills my heart, sometimes I cannot think for the want of crying. It is not my loneliness but the unnatural separation that hurts. I want to help you, share with you, give to you. I love you, John

My letter to John from Lens, Switzerland, dated March 15, 1986:

Many thanks for your letter which arrived after your phone call with the Hotex papers. Also thank you for the phone call because it gave me a lot of strength and belief in our actions. I was really sorry that I cried on the phone on Monday, normally my bad days have been limited to Fridays, but last week it seemed to go on right through the weekend.

I'm really counting the days now, only 13 to go and we will be in each other's arms again. Lucie, downstairs, has offered to look after Edward for a day when you get back "pour que nous puissions nous rattraper"! Sometimes she makes me blush.

Birgitta came on Monday lunchtime and came through Icogne, hence she got lost when she got into the village cause she mixed up the two Coops, and finally

called me from the Post Office. Gabi was a pain all week, but of course everytime she cries "Mama", Birgitta was up and out of her chair. Gabi also gave Edward some terrible whacks, but B. spanked her. She says that she never knew it was possible to love someone so much – obviously her feelings go deeper for Gabi than for Bernhard (I guess it's the same for him) and I have a hard time accepting this idolization of a child. I much prefer to idolize my husband. No, seriously, I love Edward very much and it's a different love from the one I have for you, but I never knew I could love anyone as much as I love you! I think my feelings are right, but she does too.

We both went down to Geneva and Matt arrived yesterday. Both Edward and Matt are sleeping now. I meant to write to you and post the letter from Geneva, but I needed B's help for the second side of my pullover and knitted like mad all morning. Sorry, but I do want to have it finished by the 27th. I'm very proud of it. Silly woman ...

Birgitta said I have somebody looking after me. My guardian angel? I light a candle in church each week for our finances – and one for your safekeeping. Matt, of course, is shocked by that – he has such a dogmatic view of Catholicism.. Besides that, he seems to be all right. Edward thinks his beard is funny. So we will be off up the hill and try the cross-country skiing. It is incredibly warm now and the snow is disappearing.

I've just got your letter – thank you for the way you put things. You are obviously the one who thinks out things for the two of us. I agree with you wholly and I feel that we will succeed even if we do have difficulties ahead of us.

In the mail there was a letter from the Hotel Continental to say that your candidature has been retained after the 1st phase of selection and the director will be contacting you to meet you: he knows you'll be here as of 28.3. Also a letter from the SSH placement des cadres saying our candidature for "couple de direction" for a 5 star hotel in Suisse-Romande as of May 1st has been retained, even though they wrote Swiss nationality, 35-40 years, de constitution sportive (YES!) as conditions. That makes me feel better too. So attached are the job descriptions.

On the radio a man is saying, "Men have to snore because they have to protect their wives from wild beasts in their dreams". So keep on snoring for me, my love, and I will keep my sanity for you. Apart from my psychological health, my

*bump is pushing forward to tell the world that someone is on his/her way.
Edward and I send you lots and lots of love of our individual type. Xxx Kate*

Letter from my mother addressed to me in Lens, Switzerland, dated March 19, 1986:

I hope this reaches you in time for Easter. By now you will have been entertaining your eldest brother for a week. Hope young Edward behaved well, and didn't shout too much!

Today is the Feast of St. Joseph , so we pray that he will hear our prayers and help the Father of your family sort out your problems. I feel sure something is going to turn up. It's so hard to have faith and be patient. I saw one of those little things one puts on the fridge the other day which said, "O Lord, please give me patience, but send it quick."

Time is flying fast and far too many weeks and months have passed since we met up. We'll have to try and do something. Is it possible to keep in mind that perhaps we could meet up in May or June, last or first week or vice versa! I know you have to sort all your problems out, but just keep this in mind. I have promised to take Aunt Elsa up to Castle Rising for 2 weeks this year, and I really can't go back on it. But I do think it would be possible for you to be there too. I think we could subject Aunt to one little fellow. I plan to leave her mid-May and go to join Dad at an Italian meeting on June 15th at Castiglione della Pescaia, no less, and then I have to rush back because Pat and Biddie will be in New York. The latter doesn't please Dad because he thought he and I could do some slow travelling back through France after Italy, but he only suggested that idea when he knew that I had to rush back. Anyway I am quite sure his present boss will find a reason why he should come straight back and if he doesn't, CDL will! So this is really only an idea – and somehow we'll get together.

I'd like to get some clothes for Edward to help him through the summer. I'm not quite sure of his size. I think it should be a 2T, which is Toddler 2. I thought of some Tshirts and farmer pants. We'll give you a call over Easter and pray that things will start a new phase for you and John and Edward and the little person we're looking forward to meeting in the summer. Keep well – God Bless, all our love, Mummy

Life as a stay-at-home mother and housewife from April 1986 to May 1987

An extract from a letter to my parents dated April 7, 1986:

What does a housewife do on her first day at home with hubby out at work?

Does Monday have to be washing day?

I sent a telex which I hope you got and wanted to call, but our two-year financial recovery plan now in effect, does not allow for fun telephone calls abroad.

John has got the job he wanted – F&B Manager at Ecole des Roches hotel school in Bluche. ...

So we are now permanently (?!) installed and John's salary will amply cover one non-working wife, 2 kids and paying back debts. Hooray – I'm very proud of my man. He finished off very well in Rabat and the GM gave him a very decent reference. (I say decent because of the short term – otherwise excellent remarks about his professionalism and performance). Müller also drove him to the airport and admitted that he, too, is looking for another, more stable, job. Anyway one week of unemployment was enough for John – we got more things sorted out, pictures hung, etc. – and he was really happy driving off this morning to a new challenge. He won't be teaching, although he'd like to try, because he's in charge of the administrative side of the F&B operations and head of Service and Kitchen courses. And I'm sure the students will be in fear of him – he became a real Hawk Eye in Rabat (the US marine hairstyle didn't soften his appearance!) School holidays are from mid-June to mid-July and mid-December to mid-January, but as he's administrative it's not sure he automatically gets 4 weeks each time. Hopefully he will have time off in May / June to see you properly (not looking as exhausted as always) and we could (if he has the time) join you in Italy for a couple of days. We're so close to Domodossola. So you keep us informed of your plans and dates and we'll try and fit in.

Isn't that great news?

We will be working on the household budget and planning repayment. Thank you very much for the £500. We have written to the tax people with a sob story and have hopefully delayed payment. John thinks the money from Morocco should get here sooner or later and has to contact the treasurer about his pension plan.

Many thanks for the OshKosh outfit. It's really fun and fits him nicely with room for growth. The colours are good too as HRH as an eye for dirt. Last night he went to bed at 5:45 because he was so tired. John wonders if he will ever be the cuddly type –only teddies get cuddles, and “Ma-Ma” when he's very tired and/or unhappy. We plan another photo session shortly because he's changed so much. He is very much John's son. The separation did the father/son relationship wonders and they spend a lot of time together now. Although he does get into trouble a lot – he's always pulling the books out of the bookcase, playing with the plugs, climbing onto the table, breaking things (the liquidizer was cracked the other day – John hasn't seen that yet) and he becomes quite indifferent to smacked hands. Of course, Dad is much more effective but at the end of the day we're so fed up of having to spank his hands and don't have the heart to do it.

On Saturday it snowed, Sunday the sun shone and we sat in t-shirts on the balcony and today there is a real strong wind blowing. Obviously spring is having a hard time to appear.

I have a pile of things waiting to be done. Edward wants to get out of bed where he's lying, calling “Ma-Ma”. After a while you wish he'd start saying Da-Da. So will be off and start the cleaning, but won't overdo it or John will get used to too high standards.

With lots of love from all three point five of us and looking forward to seeing you in May or June. Lots of love, your housewife daughter, Kate

An extract from a letter to my parents dated May 5, 1986:

Many thanks for Edward's gift – they are really super and just in time for the radioactive³⁷ heatwave! NO – the sun appeared on May 1st much to all's delight.

We finally took some photos of Edward yesterday on our walk and hope to have them developed soon as Uncle Mike and Godmother have been remarking that there have been no photos since this time last year. We took some around Christmastime but never got round to developing more and he's changed

³⁷ Chernobyl disaster happened on April 26, 1986

somewhat. At the moment he's got a runny nose which might be something to do with teething as his first molars are coming through. We've started "Floating Baby" course, a swimming course for tiny tots and have been for 2 lessons. He gets extremely angry with me and doesn't like being on his back at all, but the teacher is very good and hopefully we'll be all right soon. The teacher told me that E's problem is that he's too active as most babies are the opposite. He is completely exhausted after 15 minutes. I love being able to do something like this with him and plan to take him with John to the local pool next weekend. Daddy is for fun and play and Mummy is for cuddle and comfort: we've been stereotyped by Edward.

Last week I worked in the afternoons for Manpower and Edward went to a crèche, run by some lovely nuns. I was pleased for him because he enjoyed the other children's company. We've met through the school a young English / Swiss Jewish couple who've just had their 3rd. Their number 2 is 2 weeks younger than Edward and screams all night. I've offered to have him some afternoons when I take Edward for his daily trot. Maël, the little boy, is very similar to Edward, although Edward now sleeps all night with no breaks. The Swiss authorities are recommending that young children and pregnant women don't drink fresh milk. Tea with condensed milk? Yuk. Still I think it wiser to follow recommendations even if the levels are considered low. Zarina and Anna are expecting for September. I haven't talked to Anna cause she's in England, but Zarina has been on the phone complaining she's fat.

I went to H&M the other day and bought three little cotton jumpsuits for Jan, Kirstie and Laurent Aird, Katie's (Graham) triplets. I wouldn't like to be in her shoes! I asked the gynecologist what sex the baby was when he scanned 2 weeks ago, but he couldn't tell. It might help us in the choice of names as we've no idea. We had chosen Benjamin for a boy, but 50% of the Lens population is called Benjamin so John says that's out.

How are your plans for your trip over? John would like to go to England but it's such a long drive (now 1000 kms) and we tend to overspend there. So if he gets a break in June we'll either go sailing or stay here (and wait till you come). Hubert is now out of hospital after a second heart operation and plans to stay with us, and John is pushing his Mum to visit. I envisage everybody arriving at the same time.

I had the phone fixed and as long as the US don't blow up their communication satellites the line should be good. Please don't leave your plans to last minute. Lots of love, Kate

Card from my brother, Matthew, dated April 10th, 1986

The cards picture is a photo of a little boy with a rocker hair-cut, in pampers, wearing leather studded gloves and anklets, on a motorbike, that has written on its petrol tank "Born to be wild". An allusion to Edward?

Just a quick note to thank for having me. I really enjoyed my stay with you and hope you weren't too worn out.

Letter from my Uncle Mike dated April 19, 1986:

Thanks so much for your long, newsy and entertaining letter of the 10th. You have inherited your mother's flair for letter writing and added something special of your own.

Perhaps in an attempt to show me that I had progressed he included a photocopy of an undated letter I sent to him from Ringwood, New Jersey, around the age of 9. I wrote:

Dear Uncle Mike, Today is Fathers Day and all is well. Julianna is her with us to stay for a while. Grandma and Auntie arrived safely. The sky is grey with clouds. God bless you. Love, Kate

Letter from my mother, undated, around April, 1986:

Just a quickie to say I've finalized my plans. I am leaving here on May 17th and will be at Hall Cottage until June 4th, when we will make our way south in the Prelude, probably arriving with you on Saturday, June 7th. I should like to stay with you that week, but perhaps popping over to Zurich for a couple of nights and then back again. Daddy wants me to meet him outside Paris on Friday, June 13th and then go down the Loire Vally looking at chateaux. I think four days or even three would be more than enough – and then meet up with you and John and Edward. Dad has decided not to go to the Italian meeting 1) because it has become too commercial, 2) because it didn't look like I'd get permission to be with him and he didn't want to be refused, so instead he said he'd like to take a week 'chateau-ing'. ... Unfortunately I have to leave on June 20th as Pat & Biddy will be in N.York and have asked if they can come and stay for a week. It is unfortunate it is all happening at the same time. ... Did I say that Marge

Blum sent her best love, and said what a super babe you had, mind you the photos are a bit out of date. My last photos were taken in September. It is just Granny's own fault for staying away so long.

We spent last weekend with Charlotte & Steve. C is blooming and babe is kicking well.

I sent off a parcel for Edward, wishing him a happy ½ birthday and hoping the customs will be kind. I couldn't find a summer jacket, perhaps we can find one when I'm over.

An extract from a letter to my parents dated May 21, 1986:

How time goes by quickly – you called over a week ago and I've been meaning to write to you ever since. In the meantime we spent three days sunning ourselves on the boat – a complete rest – even if I forgot the new lifejacket and harness for Edward. Our neighbour at the port lent us his – as his kids are in their twenties!

We got to Brigitta's on Sunday night and Gaby developed chicken pox during the night. Edward pediatrician would like him to have it, but we departed as early as possible Monday morning to the doctor's.

So the baby's sex is unknown. We couldn't see because she/he had her/his legs together and because of the BREECH position couldn't spread them. Yes, you read right. The doctor thinks that there is a natural explanation that both babies turned head-down at 23/24 weeks and 4 weeks later turned back to feet-down position. It could be the shape of my womb. Anyway, I'll see him again in July after his vacation, during which we feel it's ok to drop a check-up, and see what he/she is doing. It's rare that the baby, which turns at +/- 30 weeks to breech position, will turn back.

All that doesn't help us with the choice of a name!

Postcard from my father dated June 15, 1986:

We visited the Pompidou Centre (ugh!) , the Louvre (formidable!) and the Folies Bergère (oo-la-la!) on Saturday and went to sung Mass in the Madeleine before setting off to Orléans. We are in a twee hotel at Tavers, near Beaugency for a couple of nights. At last summer has arrived! Sorry my visit was so short but until the next time! Thanks for the watch, the cake, the Champers. A birthday to remember always, xx Dad

Letter from my mother after my parents' visit to us in June, 1986:

I had a letter from Dottie, who has completely forgiven Edward for the beads – and who says he is a lovely child and really enjoyed meeting him. I don't think Dottie could say things she didn't mean. Anyway...

Now I am back to ordinary life after my exciting and busy eight weeks. I feel a little tired, but mostly rejuvenated but don't tell anyone – or I'll have no excuse for doing nothing, or very little, which is what I am trying to do this week. The Boss keeps watching the list of things to do – that aren't getting done.

Hope the enclosed will amuse your young son. Tell me how he likes them. Can you remember your nursery rhymes?

Give Betty my love. I'm sure we'll get on fine if she's still with you. Have a happy birthday. Lots of love to you and Edward and John. God Bless, Mum

Birthday card from my sister, Charlotte, dated July 1986:

To my preggers sis, Mummy says you have a wonderful son, quite a handful. But I hear I'll get to see him at Christmas – I hope so! I'm not sure yet of our plans but I think I'll go over early again to help Mum with shopping, cooking, etc. even though I'll be a little more tied down myself.

We're beginning to paint the baby's room. I thought I'd have it finished months ago. Anyway it will get done before August 25th. I'm beginning to panic! I don't even know what to dress the kid in! I hear you haven't chosen names but Mum told you ours! I'm hoping it will be a little Esther, but so long as it's healthy – right! Lots of love to one and all, from your preggers Sis and expectant father

Postcard from my sister, undated / summer 1986 from Long Beach Island:

Our last relaxing holiday! It's fun to watch parents run after their 2-year olds on the beach until one realizes that is us soon! I've been feeling great except for the heat. How about you? Mum says Edward is a handful! Must be hard to put your feet up!!! Love to all, Charlotte and Steve

Extract from my sister-in-law, Meroulla's letter dated July 2, 1986:

How is Edward getting on with the bump? We hear he's quite a chirpy little chap who's into everything. He should meet his cousins sometimes I wonder how we've anything left un-mutilated. ... Have you started potty training yet? We haven't been very successful so far. We enjoy it better when we wait to

evacuate our bowels during bathtime, much to Christopher's disgust because it means bathtime is cut short every time. Very infuriating!

Pebbles called round a couple of weeks ago, she wanted to know all your news and all about Edward. She still misses him. She's hoping to get to Canada.

Letter from my mother after my birthday in July, 1986:

I popped into the outlet on my way back from the Soup Kitchen yesterday – I must have smelt delightful! I went to look for a nightie. I looked for one with front openings and they looked so frausty³⁸ - that I picked up this and you can put it on for visitors and then throw it off when they've gone. If it really doesn't suit - hang on to it – but let me know and I'll try again. They may have some more in. I meant to mention on the phone that Charlotte has also had some moles that are a bit enlarged and her doctor said to wait until after the birth and see, as they tend to enlarge with the hormonal changes.

My ticket is all set for the 14th of August. I think it is the flight that comes in around 7 a.m. if you remember last time, but I'll confirm that.

Are Izod shirts of any interest to your hubby? I saw an outlet with them yesterday. I won't buy what he doesn't like. The shop assures me the winter shirts will be in in August so I hope I can bring it with me.

An extract from a letter from my Aunt Helen dated August 15, 1986:

How marvelous to have a daughter – how clever of you. It also has saved a lot of bloodshed, as I hear there were dire threats from your Father if you didn't have a girl! I do hope you are all very happy and thriving. I except John is also greatly relieved that all is over and all is well.

Thank you very much for your letter and for the photos. Edward must be thoroughly enjoying himself with two doting Grandmas. It would be really lovely to see you all but I guess that will be sometime in the future. Perhaps you will all be able to come over to England some time. When the alterations are completed at Hall cottage there should be a bit more room for everyone.

³⁸ Made up from the German word « Frau ».

When Mark phoned on Monday I was so thrilled with the news that I forgot to ask him whether Beatrix had been born on the 10th or 11th of August. The 10th August was Uncle Dave's birthday.

An extract from a letter to my parents dated September 9, 1986:

Just a quick note before milking time starts to say THANK YOU for everything you have done for us in the past four weeks.

I hope you got back safely and didn't miss each other at JFK. Did Mum's suitcase arrive?

I'm sending you a copy of the newspaper with B's announcement. I found them when clearing up the bookcase (wot? Clearing up?) along with the photos. We haven't had the film of B. developed yet (b... typical) but I will put in this afternoon (promises, promises...)

We went away on Friday and I and kids spent the day in the car while John ran around Montreux and Lausanne. We changed the loo seat for the table thing and Edward hates it. John met Barakat at the EHL³⁹ and came away with an even worst impression of the "rich kids' school". Sailing was disastrous; we ripped the foresail and came back to port on Saturday evening exhausted. But Beatrix was sorry and let us sleep from 22:00 to 04:00: 6 whole hours of uninterrupted beautiful sleep.

We visited Jennifer Caroline on Sunday afternoon. She was born on Friday morning by caesarian. Anna's waters broke on Thursday afternoon outside Geneva's main station. The following morning she was 3 cm dilated when baby started having heart problems. Anna is all right, just normal discomfort. Chris came round to the boat on Friday evening looking rather shaken and happy to have someone to talk to. He was very worried for Anna's sake. Edward lightened the atmosphere by throwing a glass of wine over Chris's trousers and we gave him fried potatoes and cervelat sausage to make him smile. Stan and Jean were reported to be very happy and proud grandparents. They're returning to Nyon in 2 weeks. Chris's Mum flew over for a look and left so Chris will be eating sandwiches for 10 days, I suppose.

³⁹ Ecole Hôtelière de Lausanne – Lausanne Hotel School

As for our children, we are getting “organized”. We have exercise and cuddling time on the floor in the mornings. Beatrix seems to be improving in looks and health. She still farts and burps constantly, but I drown her with anis mixture and it seems to help. Edward had a hard time on the boat, but yesterday he was really super and we went to a playground with Elisabeth and her son, Nicholas, and he didn’t stop for two hours. He climbed up the highest slide, played in the sandbox, stole some kids’ toys, ate all Nicholas’s biscuits, and so on. But he was happy.

Not so his father. More trouble at the school yesterday which seems to be resolved today by the lack of respect for the director by all other staff. We’re off to Luzern on Saturday to see Mr. Müller and his associate about his hotel and restaurant complex project. He called John last Thursday and invited us all up so John’s spirits are not too low.

Surprisingly, neither are mine, in spite of all the shirts to be ironed, and all the rest. I feel I’m coping although I still can’t find Edward’s rain boots. Maybe my memory will return and I’ll remember where I left them. The crèche in the village has been postponed until October because the army is occupying the old school house. John feels this is not the right moment to put him into a French-speaking playgroup because of his language-learning, but the boss (yours truly) is going to put him in even if he ends up speaking patois⁴⁰.

Peace is over. Edward is calling from his bed. When we got back from Sion last Thursday, he pushed the door open and said “Cuckoo Ga-Ga”. So from Ma-Ma and Da-Da, Mi-Mi and Bi-Bi, lots of love to Ga-Ga and Ga-Da.

I added to the same letter on September 18:

Seeing that I have only just bought envelopes large enough for the paper I thought I’d add a word or two.

We went to Lucerne and the project looks very interesting. ...

Oh, guess what? You’ve heard this before, but the boat is up for sale. It just looks like the only way to relieve the financial problems and we would invest the

⁴⁰ Swiss French dialect, hardly spoken

remaining amount in a day sailing dinghy – and not a BMW. I'll see and then believe, and won't everybody? So hang on, CDL, before you plan to blow the 15'000.- on Mummy's new fur coat (with a house like Hall Cottage, she'll need at least 4!) On the other hand we could reborrow it and maybe buy in Luzern ... I won't mention that to my husband or he'll take me up on it. Other good news about the house....

I've found Edward's wellies – they were at the crèche where I left him in June. Zarina had a baby boy, but I've told you that already. Oh – more important news. We will have the christening either on 11-12th or 18-19th of October with Anna and Chris' little girl – a double do! So I'm waiting to hear from Mark when they'll be here and then we'll arrange it. We might do it on the Saturday afternoon followed by a meal in the Parish house because it would be too difficult to get everyone in at Anna's and disastrous to try going to a restaurant with all those kids. We could of course get a babysitter No, just joking. And I will get Mark or someone to take lots of photos, not Bernhard.

*An extract from a letter to my parents dated October 14, 1986:
Many thanks for your letter and photos and money. Yes you do sound confused but you are right when you "suppose" you thrive on rushing around. To some extent I must be my mother's daughter.*

Since I last wrote we have had a couple of bloody weeks starting with John's second trip to Lucerne to present the project (on a Thursday), on which day Edward pulled one of the Chinese vases on to the floor and smashed it. It felt like the day when I turned my car over; just wished I could relive the day differently. That and a few nights of no sleep and I was feeling that I could just disown everyone and leave. Betty arrived the following week – John kept on saying how she would help – with a stinking headache which she couldn't get rid of, so she went to bed. That coincided with Beatrix not wanting to mix breast with bottle and so my breasts became engorged. The medicine I took made me sick as a dog and I got a migraine. That was the day John built a new staircase with his Mum for the kitchen and I had hammering and screaming children to cope with. Then Beatrix got constipated on the formula and was howling after each feed. And B. Betty was saying, "it's not normal, etc.". I spent the Sunday in bed and on Monday went to the midwife at Sierre hospital with 38.5° fever. The doctor wanted to keep me in hospital but filled me up with anti-biotics and I had to go back the following day for a check-up and should go back again this

week. We saw the pediatrician on Tuesday and Beatrix is much better now. I took John in with me and the doctor talked to him about keeping calm, etc. which balanced things out after Betty's raving. I have had an awful time with her – she can't handle Edward at all – and is moping around doing sweet f.a. until John comes in and then it's all, "what does my little lamb want?" which drives me batty. John and I have had a lot of talks about it and he says I should take notes or tape her so I can write the whole story one day. That's a thought. We went to the boat this past weekend and relaxed completely. Sorry to say this, but we've had absolutely beautiful weather since you left. We're still in t-shirts. So, Betty's leaving tomorrow and I think I'll start putting Edward in the crèche 2 half-days a week. The village crèche hasn't opened yet so he'll go up to Crans. I've become a bit tough since the day of the Chinese vase incident, but I find my authority has increased and he is behaving better with me, and is surprisingly very much more affectionate towards me. He pulled Beatrix off the sofa on Sunday night, but I don't think he'll do that again. She wasn't hurt, thank goodness. She's all smile and gurgles, like Esther, when she's not crying and we're becoming friends. She smiles for her Dad so she's learning quickly. She's nearly 5 kilos now – what a weight, and her hair is calming down. I'm going to get a new stroller because the old one is really falling apart so before you think of Xmas presents, maybe you could make a contribution towards that. I want a light McLaren one that will hook together with Edward's so I'll be looking around.

John should finish work on December 15th and we'll leave the following day – Tuesday, the 16th, for Brussels. We plan to stay there two nights and then leave on the 18th for England. Betty isn't sure if she'll come with us so I don't know whether we'll be going to Hove to see Den and Don, but I'm sure we will be up in Kings Lynn by Sunday. When are you planning to fly over? ...

John has heard from Müller that they have been retained with two other groups after the first selection and he should know by the end of October whether they've been accepted.

John and Edward bought me a new steam iron.

Birgitta is pregnant and expecting for the first week in May. She would like her Mum to come down and look after Gaby, but she doesn't think she'll get her for more than a week so I said I'll reserve myself for emergencies. She wishes she

had a Mum like mine. I wish I had a mother-in-law like John's ... but am so happy to have a wonderful mother. John thinks Beatrix is really an Anne. Thanks for your photos. What a turned-up nose B. has. Esther is really sweet. I wrote to Charlotte commiserating. Now I'm flat-chested again and wishing I could have gone on. Maybe with number three

Later:

Betty left and the place seems empty. Apparently she has a nerve inflammation in her head which caused the head-aches so her doctor has given her some medicine. I'm sure she won't be back until Edward is about 2 ½ - so 8 months to go.

I've just had two sleepless nights again and am just drifting around the place. I fell asleep at the end of the yoga class last night and woke up when everyone started to leave.

I might be taking up a part-time job in Sion in the afternoons for three hours. I can put both my tots in the same crèche (run by nuns, it's also a school for nannies) and that way we'd all get a break. I don't know if it would be worthwhile financially, but I'm hoping it will. They might potty-train Edward for me too!

Have just finished cleaning the downstairs room (that Mark and Meroulla used during their stay). Edward smashed another lamp, but it belongs to the old lady. I'll get it replaced.

Edward fell down the stairs on Saturday from the top to below Lucie's window. Martial will have the gate finished for tomorrow. Edward is all right. It's his mother who had the nervous breakdown, as you can imagine.

Beatrix slept from 22:00 to 06:00 the past two nights, but Edward woke us up three times. You can't win! Must go and feed the Screamer. Lots of love, Kate

Letter from my mother dated October 6, 1986:

So many thanks for your letter and all your news. I hope all sorts itself out for John. Luzern is such a pretty place. It hasn't been an easy year but things do have a way of working themselves out. ...

I am delighted to hear Mark & Meroulla are coming out for the baptism. How I wish I could be there too. It will be nice to have some members of the family to support you, and I'm sure Beatrix will look beautiful in the gown.

... I was bushed, am still a bit that way. Everything has piled up, and now events are looking up and decisions are having to be made. It will only stop when I'm laid to rest and I hope I have a long way to go yet. I really thrive on this I suppose – I just fantasize about a life of ease and relaxation, infallible organization and I'm always on time! So perhaps now you understand the first part of this letter. First things first. Write to Kate. ...

Just read your letter again. So glad to hear that you feel you're coping. God takes care of you, he really does.

Letter from my mother dated October 29, 1986:

Dear Kate and John,

As you will recall, during this past year I have talked to you about Christmas presents. This year, God willing, we will all be together at Hall Cottage (and some in Pottles)! Dad and I have talked together and for us it is very important that amidst the piles of present giving we do not lose sight of the reason that we come together at this time of the year, which is to celebrate Christ's birthday. In celebrating His birth we also celebrate our own births with thanks and joy and especially this year when we will have two little granddaughters with us.

So to get back to the present business In earlier years Christmas presents tended to be what you couldn't afford yourselves, but to be honest this isn't quite the same anymore. So I will still choose you each a gift with loving care – (specific requests are always welcome). Size and originality will vary with Mother's cunning and thrifty shopping.

We are looking forward with love and joy to this Christmas fully aware that with 14 persons, there may be some bumps.

It was good talking to you and hearing about Beatrix's baptism. How we longed to be with you at that ceremony. Still we shall be able to watch it on video.

Extract from a card from my mother-in-law, Betty, dated November 20, 1986:
I do think of you all each day and do pray that little Beatrix is accepting you all at last. Give them both a big kiss from Gar-Gar and tell Edward that I have at last found a cow, not all black through, with white patches).

Letter to my parents dated November 23, 1986:

The snow has fallen for the first time this year and the village is all covered in white. Winter is here.

I'm writing to you for a reason and I'll try hard not to be emotional. You know and I hope appreciate that I find it hard to ask for favours. To start with you'll find on the back page a summary of our financial year. I have to send it to you because I need to know that you know what it's really about. I know that in August I made allusions to our financial status to Mum and how I thought we could have done it on a tighter budget, but now that I've just written out where the money came from and where it went, nobody here went overboard with spending 13'000.- on living.

Now that the end of the year draws near, annual payments rear their heads and cash flow creates a problem. Well we have enough to cover all the end of year payments, including some of next years insurances which should be paid on January 1st, but there's nothing left, but the 60 francs in my wallet for December and January, and an outstanding bill for 1'700.- in taxes that can be put off for a while – I've had the OK from the tax authorities.

John has written to his father twice now asking for financial help and there's no sign of even an acknowledgement of his letters.

We've spent 200.- on ads for the boat and have followed up all signs of interest. We've even lowered the price to 65'000.- and now have one person interested (maybe). The boat cost 88'000.- four years ago and we added 10'000.- of material. Under 65'000.- would really be pushing it, originally we wanted 75'000.-.

So now we are at the stage when we are going to start selling jewellery and furniture to get us over the hump.

We're also at another turning point job-wise because we really must get John back into the hotel business or he'll be earning 4'500.- a month for the rest of his life and will go nuts in the meantime. So we'll be moving again before Easter comes around. This means that I can't start working (we have talked

about this long enough) and that our cash flow won't have time to adjust itself before we leave here.

I'm writing to you explaining because John can't bring himself to talk to anyone but me about it. I think Daddy will understand this because it is all tied up with a man's pride and John doesn't feel proud right now. I am proud of him because he has looked after me and my children during this past year and tried to cause us the least possible distress. If I had not been pregnant maybe he would have taken the risk of staying in Rabat and looking after his career first.

You know how I hate to have debts and to be insecure financially. When I look back at the life we had in Geneva I laugh to think that I used to complain about a lack of money. Three years ago we had put so much on the side for "in case" that we spent 6'000.- of it on my Panda ...

So I'm asking you to help us through the next two months and especially Xmas. I don't know if I'm asking for a hand-out or a loan because I don't know when we could pay you back. I don't want to ask you to pay my bills, but to help us pay the food and our trip to England to be with the family for Christmas. And believe me I hate having to ask. But it's easier on paper than over the phone where I would dissolve into a flood of tears – typical Kate behaviour. But I guess we'll be talking soon, so be warned. Until then, lots of love, Kate

Letter from my mother, early December 1986:

My dearest Kate,

Many thanks for your letter. I do know how hard you have tried this and am wholly confident that you will get things worked out when the time is right. We are happy to help you – that's what loving one another means – it's no good going to soup kitchens and neglecting those at home.

I am so looking forward to seeing your pigeon pair. Beatrix must be nice and chubby. It's going to be such fun seeing these little girls together and the little boys. There is a present in my suitcase for Edward for his birthday so we'll have another birthday party on Sunday 21st. Luke, Chris and Alison should be with us.

Time races by. I am so looking forward to us all being together. Lots of love and kisses. God Bless, Mum

Extract from a letter from a friend, Helena, dated December 1986:

I won't put the date because when it finally gets posted a great lapse of time is likely to have passed.

I'm glad you had a girl this time, much more expensive, she can't wear only Edward's cast-offs, but she will have big brother to look after her when she gets older and when they get past the beating the hell out of each other stage. I suppose Edward gets up to lots of naughty things when you are in the middle of feeding Beatrix.

I'm glad to hear John has seen the light and got his own back on Hilton. I hope they realize what they have lost, just to gain a few pricks like Brand and Begert... Anyway I wonder how they are all getting on, of course the standards are bound to have dropped. Ha ha!....

I hope you won't ever shorten Beatrix to TRIXIE.

Extract from my mother's letter dated January 7, 1987:

Thank you both so much for coming over. You have a lovely pidgeon pair. It was good to have Edward without competition for a few days. Beatrix is a love, completely won Dad's heart. Give them big kisses from us both.

Letter to my parents dated January 22, 1987:

*Ecole des Roches⁴¹ from the desk of a very bored receptionist cum telephonist
This news merits to be phoned across the Atlantic, but as you are momentarily across the Pacific, I hope that it will arrive across the A when you get back crossing the P.*

We are moving, at least to start with, John is moving back to civilization, i.e. Swiss civilization, down in the valley next to the water – Geneva. John has just accepted the job he was interviewed for in February last year at the Bahnhofsbuffer⁴² in Geneva. At that time they took on an older man with more experience who apparently has ballsed things up incredibly, following a piss-artist who has just been fired. The former, former director has still been keeping an eye on the business as the owners, Mr. and Mrs. S., are reaching retirement age and Mr. S.'s health has been on the decline and he wanted John in the job. You should have seen his face this morning when he told me: I thought he was

⁴¹ Hotel management Les Roches, Bluche where John worked

⁴² The train station restaurants

going to burst. The director here, Mr. Schlatter, has accepted just one months notice so that John can start on March 1st. The bad news is that I have to stay here, molding away, until the end of February so I won't be able to look for an apartment until March. Still I'm earning the top salary of 17.- frs an hour and bills are being paid. Edward and Beatrix are being looked after by Sr. Marie-Boscoe and have settled down quite well, although they are very tired, as are their parents, when they get home. When we got back in January we found that John had only been paid half of his salary because he took two weeks holiday (which were his due). Although the school has admitted that it was a mistake and the other half should be paid, they still haven't done it so it's just as well that I'm working. John will be getting 6'500.- to start with and 7'000.- after two months in Geneva. And as he says we won't be poor anymore – when we've paid off all the debts. So – as my post-it note said – “Are we having fun yet?”

....

A lot of things remain to be discussed, like whether we will keep the flat in Lens and use it for holidays or rent it out and with the rent pay for the heating, etc. I am so excited I could jump up and down. On the other hand I think I will go quietly to church this evening and light a candle for a reply to our prayers.

Beatrix is really living up to her reputation of the “rare pearl”. She weighed in at seven and a half kilos two weeks ago and 65 cms long, but she is so beautiful. Edward had a bad attack of bronchitis and is on antibiotics. As soon as he's over that, I want to take him skiing, hopefully this weekend, and I will have to use his Xmas money for buying his skis (proper, not plastic ones), but I'm quite confident that he will enjoy it. Nicholas, his pal, is skiing happily now and they are very similar in their physical prowess. It will also give me an excuse to get my skis out of the attic.

So if it wasn't for me sitting on my backside boring myself to tears in this tedious, even if lucrative, job everything would be wonderful. I'm less tired at the end of the day from “working” than from staying at home “just looking after the kids”.

Edward thanks Granddad for the postcard and says he'll write later, much later.

Extract from a letter from my uncle Mike, dated February 15, 1987:

We are absolutely delighted to hear of John's new job and hope very much that you will find the right place to live. Do wish John all the best from us.

Extract from the letter to my parents dated February 3, 1987:

Beatrix is a little "chesty" and hates the inhalations. She's very happy to be home. Sorry if I wasn't very attentive on the phone on Saturday, but I was getting the eagle-eye from you-know-who.

We had a guy round last night for a quote for the moving. He thinks it should cost about 1'200.- which is worth it. However I'll do the packing because we have to separate the things that stay in Lens from the things we're taking down. I'm really looking forward to going back to Geneva, not the moving, and living amongst my friends. I've had enough of Lucie's company although I'll miss Elisabeth and son, Nicholas.

I had a letter and beautiful home-made ABC wall-hanging from Kate Graham. She has to go to England with the baby who needs a kidney operation in April. Will you be there? She has a full-time nanny and makes children's toys in her "free time".

Extract from a letter to my parents dated February 25, 1987:

So we're on our last week of work and John is off on Monday, or rather Sunday evening, to Geneva. We still haven't got a flat, but have our name on a waiting list for a place in a "good" area in Geneva. Monique B. went round to visit it for us and said we should jump at it. It's empty, but the agency are checking up on our references and stalling so it's doubtful. The price is all right (2'300.-) and it has three bedrooms. John said he would call again this afternoon. I'm starting to have dreams about finding flats with landlords like Viktor, otherwise known as nightmares. John will most probably stay with Birgitta and Bernhard, or Anna and Chris. He hasn't decided yet. He was hoping to get the guest room at the Parish, but there are quite a few visiting priests coming during the month and some overlap so they need the guestroom. They still haven't found a replacement for Richard.

We have had another heart-breaking stay in hospital with Beatrix. She went in last Tuesday and had her hernia operated on on Wednesday morning. I visited her on Wednesday lunchtime and she was functioning well. On Thursday she

was fine and the doctor said I could take her on Friday. So I went down on Friday and the nurse said to change her before leaving. I nearly fainted when I saw the scar. Then I could have killed somebody, like the doctor, but nobody was around at lunchtime. The nurses had to take over dressing her and assured me that it will clear up and there will be no scar left. It is about six centimeters long. On Sunday I got a friend who is a pediatric nurse to have a look at it, and she said it wasn't healing properly. So I nearly fainted again. Then I called up the doctor on duty at the hospital and all he could find to say was "well, it was very big". As if it was my fault that the doctor kept on saying that we should wait for the operation. I showed him the hernia in the first week of December and again the beginning of January long before she had her asthmatic bronchitis. He could have taken her in then as it was pretty obvious that it wasn't getting any smaller. Anyway John took her down Monday morning and she had an allergic reaction to the cream I was using to clean it. So now we have a new cream and it has started to heal nicely. Roll on the move to Geneva, and back to Dr. M. who looked after Edward. The doctor here is very pleasant, but he just doesn't listen to you. Typical bloody Swiss Male Chauvinist ... as Dad would say.

Did I have it too easy with Edward in spite of his bronchitis attacks? I am terribly nervous about Beatrix now and I never planned to be over-protective and worrying. I feel as if she is so fragile. Poor Soeur Marie-Boscoe worries almost as much as I do about her. Still she seems to be on her way to recovery and like I said, to Geneva.

I have set the ball rolling to find an aupair girl. A friend here has a super Swiss-German girl, 19 years old and who did a Hauswirtschaft apprenticeship. I know what you're saying, Dad, something rude like she could teach me a thing or two. So I have had a sign put up at the school in Solothurn for a girl and hope to get some response. I think it is a much better solution so that when I get home in the evenings I don't have to start ironing and the rest. Also if John has time off during the day he can go home and be with the children which he couldn't do if they were in a crèche.

I have applied for a job with Digital, but still haven't had more than a letter telling me to be patient because the ad had so much success. The position is training and development specialist for personnel training so it would be very interesting.

You can see that it's all plans and no-go at the moment. The new BMW has been excluded from the plans by my husband who is now in charge of the budgeting and expenditure. I can no longer fiddle the accounts in my favour which is a shame, but although I still do the book-keeping it's nice to have the responsibility of budgeting off my shoulders. John is even planning to pay you back before buying the BMW

The latest gossip is that Roest has been telling people that John is going back to the Noga Hilton as F&B Manager because the F&B Manager who took over from Roest has just been fired for incompetence. I think they are terribly over-confident to assume that John would accept when they know he's accepted the job at the Buffet de la Gare. The poor bloke who's been fired couldn't even get a transfer to another Hilton so Felli let him go on holiday to the Far East for an interview. They really are the pits. And I'm not letting John go near the Quai du Mont-Blanc.

Mark and Meroulla have been on the phone, as well as Lukie and Chris, quite a lot. They called just after you left and told us about Brian Harrington. That is a terrible shock. I hope his health will improve. Poor Jenny must be having an awful time. I said to John the other day I don't know what I would do if something happened to him because he is always the one to calm me down when something happens to the children. I have never experienced such heartache as with Beatrix, although I felt a great deal of anguish when he had his problem in December when the (same bloody) doctor doctored his foreskin. When he came back from the hospital I swore I would never be hard on him again. That didn't last long I guess but it's so scary to have a sick child that a sick husband doesn't bear thinking about.

Edward is now talking in French saying ca-ca (no guesses) and "c'est cassé" ("that's broken") and has fallen in love with a little girl called "es-i-ca" (Jessica) at the crèche. Mum is forgotten. Beatrix sends you a big smile and lots of love from the rest of us. When are you coming to see us?

Letter from my brother, Matthew, dated March 17, 1987:

I hear you are moving back to the city – couldn't take the peasants anymore! Don't blame you. Sounds like John has got a good job – hope it's going well. Have you found a job yet? Time you got off your back... and started work

again! ... Is there any chance that I could come and visit you once you're settled in Geneva? I need a break and was hoping you'd be prepared to have me. Please give it a thought and I'll get in touch soon or drop me a line letting me know.

Letter from my mother dated March 23, 1987:

Well, you must be all together up on your 13th floor. I do hope all went well on the day of the move and that you are nicely settled in. I'm sure John is very happy to be all together. Thank you for your nice long newsy letter which arrived just after our phone call. Poor little Beatrix, she's had a rough time but I'm sure she'll pull through with her guardian angel and her Mummy and Daddy watching over her. I keep looking at the Christmas photos and wishing I could cuddle her – which I will before not too long. You can chat with Dad about it, probably after my visit to UK in May. I hope Edward isn't missing his girlfriend too much. Have you found a new play group for him? I wonder too what you have done about an aupair, whether the Yugoslavian was any good. It would be rather nice to have one who would go home on weekends. And the Digital job – we passed their N.J. HQ yesterday. It's like a Walt Disney Castle.

Letter from my mother undated, April, 1987:

In haste between sewing a new wardrobe, I just had a thought. Dad was talking about a fellow we met in the Far East who had a Philippino maid and said that the sort of girl Kate needed. Well, that jogged my memory. There was an English couple who came to church who were friends with the Denny's. He had worked for Dunlop and then Juvena in Geneva and Zurich, and around the time we left, he was unemployed, but planning to stay in Switzerland. Well, she had had a whole family of Filipino girls from one family. In fact I think she had had the first three, and there were five to come. Something like that, all are aupair girls. She was always asking if anyone wanted a good reliable girl, so I just thought this might be of interest to you. They are all of a well educated background. The lady's name is Norma Mym, husband, John, and their telephone number is 01 9802570. they lived in Fallanden. If you can't find them you could always call Pam. They were long-time friends.

Just a thought, it may come to nothing, and perhaps you'd rather an English girl.

Meroulla seems to have found a good one. She does things like painting and potato-painting with the kids, not great on housework, but the kids are getting more mental stimulation than telly watching.

Must back to the sewing. If you have a chance go and see Crocodile Dundee and Outrageous Fortune. Both good for forgetting this troublesome world for a couple of hours. Big kisses to E and B. Thinking of you all, constantly in our prayers, love, Mum

Back to work – May 1987

Letter to my mother dated March 31, 1987:

No doubt you'll get a lot of news from Dad, but knowing men you won't get a lot ! Edward and I are sitting in bed, me writing and Edward drawing, and it's only 5:30 p.m. but I'm dead. I started the week too quickly and got all my washing and ironing done yesterday, plus had an interview with DEC. The personnel manager told me to call him Thursday morning, but also said that I could be "confident". Tomorrow the telephone is going to be installed so I can start actively looking for someone to look after the children. I interviewed a rather fat, 18 year old, blousy blond Nanny from Coventry whose musical hobby is playing the trumpet in a marching band, rather sweet, likes telling toddlers off, and a bit boring. I couldn't have her at the breakfast table even if I could afford 1000.- francs a month...

I will have to travel somewhat with this job (until next year when they finish the new Geneva training centre) and need someone who can sleep in from Monday to Friday. Otherwise, they (DEC) pay well – between 4'500.- and 5'000.- - and the team seems pleasant enough. I'd be helping take some of the load off a Swiss-German woman, Judith, who is very interesting and who wants to work with me! I said to John afterwards that I wondered if I could manage working with professionals after mucking about in Hilton and he said that's how he felt with his new job, wondering "will I meet their expectations – will I make the grade?" I hadn't been too sure about Digital, but I figured if I had to work I'd better get a proper job. And I thought of Mark who felt he'd been too "cool" when he really did want a job. Result: I was really nervous!

The flat is marvelous – there's so much room. I'm very pleased about it and the area isn't too bad for someone with young kids. The pediatrician is 5 minutes walk across the field. There are lots of play areas and a garderie-jardin

d'enfants. I want Edward to go in September, but the woman said that here in Geneva there are 2 years of "école enfantine" and as Edward can't start until September 89 he would then attend kindergarten for 2 years which she thought was one year too much. But I think I'll insist – it's a hundred a month compared to Montessori's 300.- a month and it's just opposite.

Edward is really progressing with the language and we're communicating! Everything is "à moi, ça": "it's mine", and he has tantrums if he doesn't get his way. Beatrix spends a lot of time in the walker pushing herself about. Edward pushes her under the kitchen table and they play "coo-coo" and there are screams of delight and laughter until he gets fed up and goes off leaving her stranded and angry. She has her good and bad moments, and Edward hasn't understood when he should "leave off".

I see a lot of Anna cause Chris works down the road and she pops in, which I find great. (Such a "social life"). I haven't seen so much of Birgitta for (1) her life is "organized", she's only available on Mondays, Wednesday afternoons and Thursdays, and (2) she has got something against Edward and he gets uptight – which makes me rather anti at the moment, a persisting feeling since I stayed with her for a week in October. Being pregnant makes her, like us all, more ratty. However I've invited her over for lunch this week and then Edward is on home ground and can do what he likes.

Mark called John and told us that Matt wanted to come and stay. The following day Matt's letter arrived with the request to "put up with him". I'm waiting to find out what's happening with Digital before replying. Do you want to plan being here with him so you can do things with him while we're working? Maybe it might be too much if we have a live-in nanny ...

We're renting Lens out for a year to pay for the tank revision and to give ourselves a break. I really don't miss the people there. We went up last week and stayed the night. I'll go back up and clean it up. We're renting it to a Scots girl who's working as a receptionist at the school. She has a brother who had a similar accident to Matt's, but who has to have live-in help so he gets au-pair girls from Germany. Chris said we should use the money for 2 weeks in Barbados. I hope it will be more like two weeks in New Jersey before you go. We had Sunday lunch with Jean Buck on Sunday. Stan (Captain Kins) starts on May 1st and has a 3-year contract. Jean is really looking forward to not

working in London and has plans to attend courses at the needlework something-or-other and do lots of fun things. She hadn't realized that you will be back in the following summer so she said you could have weekends in London against weeks in Castle Rising. Looking at Anna and I, she said it could be 29 years ago you and her in Woking, and how glad she was that it wasn't!!! Edward absolutely dotes on Anna and he took a shine to Jean. He got a book and climbed up on her knee and gave it to her to read. Very forward. However she has the right "Gran" touch! Edward's canines are finally breaking through. He's now climbing over me saying "yum-me-yum". Now he's bitten Beatrix. Time to go. Many thanks for the Easter and Aussie gifts. Lots of love, Kate and gang

Letter from my father, dated April 11:

It has suddenly struck me that by asking me to babysit your two monsters, that I really am a proper Granddad. And that thought is very comforting and full of much emotion. So thanks for trusting me to look after your two precious little people. I hope they will not suffer any deep neuroses over waking up to find a less-than-competent white-haired old fogey in the apartment and have nightmares as I did for years over waking to find a nasty old nanny breathing over me!

It was super to spend a few hours with you both. I came home with a full cold which is now beginning to go. Have a happy anniversary, Easter and hope BB behaves himself. All my love, Dad

Letter to my parents dated April 13, 1987:

The sky is starting to clear after three days of rain and drizzle and Edward thinks it is definitely not time to go to bed. He's been ill today, vomiting, and with a slight temperature so we've been stuck at home. It gave me a great opportunity to clean before the arrival of "la belle mere" tonight. Yes, Betty is on her way and should be leaving on the morning of the 16th when Matt arrives. I told John that if she wants to stay over Easter she goes on the camp bed in with Edward and Beatrix because Matt needs his sleep. But I also said to John that I hardly imagine Matt having the time of day for her. I dread to think how he'd react to her social graces! Still – there's hope – John agrees with me. Be happy, Dad: we took Edward for a haircut on Tuesday and he had a "proper little boy's haircut". He looks very grown up. Yesterday morning he came in and got into our bed and we had a marvelous conversation.

Edward: Mama?

Kate: Yes, Edward

Edward: Yum-i-yum, Mama

Kate: Are you hungry?

Edward: Yeah

And John dissolved in laughter.

We finally communicate!

I put an ad in the newspaper for an au-pair and I've had one girl call. What are you doing on May 1st, Mummy? Because I've got the job! I made a presentation yesterday morning on "Suggestology" and was offered the position of Education Services Specialist an hour later. The salary makes me dizzy: 5'800.- a month! And I'd asked for 4'500.- ... I'm very happy. And so is my husband! Plus we've decided to manage with just one car. John has such a good time on the bus last week that he's offered to take it every day.

Edward and Beatrix are now out of bed and watching the news with me. I think I'll get Betty to babysit for us so I can go to see Crocodile Dundee with my hubby. Hope Dad has recovered from the responsibility-laden task. Birgitta should have her baby any day now. She's very worried that something will go wrong. She nearly smashed the car up on her way here for lunch yesterday. Never pregnant again! Hopefully! Big kisses from my two angels – Lots of love, Kate

Postcard of St. stalls in Singapore from my father dated May 9, 1987, and addressed to Beatrix and Edward:

Who will arrive first? This postcard or me in person? Hope you survived being looked after by Gran – I doubt she'll ever be the same again. Tell your Mum she owes me 6 days rent of Gran x 100 SFr/day = 600 SFr plus wear and tear = 1'000.- SFr less food and lodging of 100 = 1500 ! See you soon. Love, Granddad

Ps. Has Mum bought a new bed for guests?

Letter to my mother dated May 17, 1987:

Well, I'm back from my holidays and have got two days off. The course went well and I was happily surprised by the quality of the trainer's teaching. The hotel has changed hands twice since 1976, but the service was very attentive

and the food yum-me-yum. Oh and I slept through the nights. I came back and found happy children – and happy Jackie – and tired John. Edward spent the first two nights sleeping with John. His face is healing quickly. Yesterday I took him for a walk – without pampers – and he didn't wet himself until we got home. Grandad seems to be well – I'd be dead after such a long trip. He bought a dinosaur for Edward.

Thank you so much for being here and helping me through my "teething problems". Jackie and John managed very well – and I think John enjoyed the responsibility. I called twice a day. Jackie didn't feel that it was too much. So thank you again for all you did. I hope you managed to get everything done at Castle Rising.

Letter to my parents dated May 20, 1987, from my office:

I'm in the office way before anyone else and thought I would have a go at word processing on my terminal. How are you? I heard from Mark on Sunday (he woke me up from my snooze on the sofa while children were napping) and he said that you had delayed your departure because Daddy was rather tired. Did you get everything done?

I had planned to call on Monday evening after my personnel dept. dinner and got home early, hoping I would be back before John and the kids. They went sailing and ended with a barbecue with Anna and Chris) but I had forgotten my front door key and had to wait outside until 10:15 until they arrived, by which time I was rather put out and went straight to bed.

Work is going well. I've already come across my conflict partners, including the bunch of bitches who taught me on the course for Teaching English as a Foreign Language four years ago. They tried to put me down the other day as my boss, Remy, would like for me to take on the English language teaching for this project, Declink, which I will be co-running with Judith, my working colleague. Anyway they forgot one thing, i.e. that I'm the employer of the English language teacher for this project if I can't do the teaching myself so I think they have just lost about 4'000.- of income. Out in the boondox here, or deep in the jungle like at the Noga Hilton, you learn how to survive very quickly.

Talking about the Noga, the girl who replaced me has just resigned. The youth of today have no staying power! Maybe she should have had Old Lendi to contend with ...

I'm still amazed at the amount of aggressive ladies here and I say aggressive, not assertive, because there is quite a lot of bitching, especially over in Personnel where there are about 20 women vs three men.

I've been on four courses. I overdid it in two weeks of work. I sat in on eight days of courses. By the last day I was so whacked so I shot off into town and spent a couple of hundred in the clothes shop, picked up a Big Mac and felt much better. The following day, I let Jean take care of my hair and now I feel human. Or I should say I felt human on Wednesday, but as yesterday was a day off I emptied Lens with one of John's employees to help me. He is built like a fridge and carried the marble-topped chest of drawers down the stairs all by himself. But the driving of this massive truck had to be done by me, and I think I now qualify as a truck-driver. Boy, do my arms hurt. I also managed to bash into the house next door and took a stone out of the façade, but it's high up and unnoticeable. Lucie and Martial were very happy to see me and said they would try and help us sell it. ...

No new boat: we have decided together that it would be better to invest our money so that in three years time we can take over the buffet de la gare. Mrs. S. told him that if we had 200'000 francs we would be able to take it over and that we would be helped by them and their associates. (him being John).

Jackie is doing fine with the children. They have really taken to her and she has a really nice way with them. We are still planning a trip to Ikea but as she goes off on the weekends with her friends all over the place, the time hasn't been found. I've met some of her friends as they come over from time to time and stay for supper – if there's enough food.

So the blue cupboard is down from Lens and looking very nice in the hall. Everything seems to be taking shape and getting organized and I feel so much better. Thank you so much for helping us out in the beginning of May. I don't think I was such a great hostess when Daddy came for the weekend, but I really was running out of energy. I seem to have re-stocked and will be in better shape when you come in June. Let me know the dates, I brought the other spare bed so Mummy can come too. We have confirmed our holiday dates and are definitely going to Spain from July 27 – August 11. Hooray!

Thank you again for all your help and support, and lots of love, Kate

We took our two-week holiday with Jackie in Rosas, Spain, staying in the downstairs apartment of John's employers. I have photos of Beatrix trying to climb the stairs to the upstairs apartment, the way small children do, looking behind her and trying to go faster than we could catch her. When we got home from Spain, John was fired from his job by the owners of the restaurant complex where he worked. I have no written documents but if my memory serves me well, the story is like this. When he was hired, he had found some legal issues related to the payment of employees' vacation, and had redressed the situation in favour of the employees. This wasn't appreciated by the owners and they had their lawyer write a most insulting letter. He had three months notice and was expected to work every day thereof. It was a difficult time for him. I became the main breadwinner.

Letter from my sister, Charlotte, dated August 12, 1987:

So Beatrix was a year old yesterday – how exciting! Did you have a cake etc etc? I'm not sure where we'll be for Esther's birthday – probably in Davos. Ursula D. who we'll be staying with in Zurich is letting us use her house in Davos for a few days peace and relaxation. I think we're going to need it. As usual we have a load of people to visit! Anyway I just wanted to let you know we'll be arriving August 23rd in Zurich. I'll call you but in any case Ursula's phone number is 2027255. It seems more certain we'll arrive Friday the 4th. Steve wants to stay a day in Berne, so he may or may not come with me. Is there any chance you can arrange for a crib for Esther? Do you have a spare one? Or can we rent one? I'm bringing blankets and seat for her that goes on the table. Anyway gone are the days that we can put her in a drawer! We have rented a car so I'll drive down to Geneva. Anyway I'll call you from Zurich. Love to all.

Letter from my sister, Charlotte, dated September 30, 1987:

Thank you so much for a great time. I really enjoyed staying with you and getting to know you all a bit. It's funny how I forget when I left home you were 17 and we basically haven't seen each other much at all in the last 10 years! Let alone the last 4! But it was great to chat some and exchange stories. I naturally have seen it only from one perspective – mine! But it was good to hear your perspective too! Coming home I really missed having you, Kate, around to talk

to. No sister to share baby stories with and watch Edward & Beatrix & Esther grow up together. Oh well I guess that's what happens when we all live in different countries. I did enjoy sharing all those things.

I hope I didn't make you anxious about Beatrix's weight. Maybe it's my own hang-up. I do worry about Esther especially as she's such a finicky eater!! So Superwoman and family, keep well.

Letter to my parents on January 17, 1988:

We are doing fine although Poor John has broken his lower rib from coughing! When we got back, his flu was just developing, but he had a lot of photo work planned and didn't have much time to rest. By the end of the week, he just coughed non-stop until something went crack! He finally saw the doctor this Friday and has been given very strong medicine to get rid of the cough, real knock-out stuff.

Yesterday I took Edward skiing, up the lift and down three times. He has so much fun. The snow is very scarce, but we found a beginners slop 30 minutes away from Geneva. Photos will follow.

We've also been through a tough training session to get them to sleep in until 7 a.m. I got so angry because by the time the first weekend at home came around, it was no longer 6 a.m wake-up, but 5 a.m. So, with the encouragement from the pediatrician, we had spanks in the kitchen and when calmed down, back to bed. This morning Edward woke up at 7:00 and Beatrix at 7:30.

We rearranged the sitting room, bringing the furniture towards the kitchen, around the fireplace so the window area is climbing frame area. We bought the open shelves from Ikea and put the coloured boxes with toys on it. Memories of Myriam Staub ...

Work is going well, although I had a confrontation with Remy (my "big" boss above Judith) who has been giving everyone shit about work performance for quite some time. So I asked him for a little encouragement and support, and not always a kick in the backside. So we have renewed our contract to work together. He said he did want me in his team. I have a hard time with Swiss men – and they have a hard time with me. I'm running my first management course at the end of the month – cross your fingers for me!

I got off all the papers for a nanny and am waiting to hear. 800.- francs a month is normal pay. I think Jacky is also looking around for a new job. I know a change won't be easy. I plan to take time off with the new person, but I won't pay 1'000.- a month to be told Beatrix is a pain in the backside and if you don't spank Edward at lunchtime he won't eat, "the little sod". Especially when I've asked her to be positive and to tell me when she has had or will have a problem. On Thursday she broke the handle off the pushchair and didn't tell me. Well, it's like that continuously. So change of scenery – change of attitude. I did want to take a long weekend with John in February, but as he can't ski and I don't want to leave the kids with Jacky I guess I'll take a long weekend with the new nanny.

I'm sorry that you seem to be brooding over Xmastime, thinking it wasn't satisfactory. It isn't easy as a full-time worker to get in a car and drive across on Xmas Eve and join in the full swing of family life, but that's my fault and I've learned from it. If I make remarks like "We'll see about next time" somewhat flippantly, I do mean it. I love to spend time with you, and I think 2 weeks in the summertime would be far more suitable than to see you for a week at Christmastime when the kids have to stay indoors cause it's cold and the days are short. I know that Xmas is "family" time, but wouldn't it be more enjoyable for you when you're back in England to have visits spaced out apart? Even if we still managed to get over at Xmas, our expectations wouldn't be so high. (Besides all this, in future times, I don't know if we can finance 2 trips to England per year.) As I said to Daddy, once we got over Xmas and my kids calmed down, I really enjoyed being with you. I don't mind shopping and cooking. I don't expect to have everything served up superbly and to be waited upon. However I can't plan and do things one after another with children hanging around, as you know from 30 years ago. I still think we managed very well during our week together.

Am finishing this off in the departure lounge at the airport. I was to hoping to find a post office, but no. I'm on my way to Nice and on to Valbonne to do a course on Time Management with another trainer. I'm just away for one night, but next week I'll be gone all week. Just the idea of next week gives me butterflies.

I talked to Connie Fallon yesterday morning and she said she's sure we'll find someone for March 1st. I'm getting very nervous – hence anguished and

unhappy – with Jacky. I can't face the morning fights with Edward and the threatening remarks she makes to him. I'm shutting up because of next week. I have a feeling that she might pack her bags and go and I don't want it to be during my first major course. In February I'm not away – all my courses are in Geneva so it would not be impossible to cope without her. There's also a service that helps out in emergencies – and there's the crèche where they know us. Maybe I should have foreseen this in December in spite of her telling me that she'd be all right after the holidays. I hate to go on about it to you. I feel awful about the situation. I find it good to talk to the working mothers at Digital who are used to it. I guess I'll become more hardened. I talked to an American-Cuban girl Josy on Monday afternoon. Her 4th girl in 8 months had walked out on her over the weekend and she'd smashed her car up in the morning. Life could be worse!

Looks like we might be boarding – 15 minutes late. And I see my favorite Swissair asshole at the boarding gate. Here goes. Lots of love, Kate
PS I am not asking you to come over and look after my kids.

Letter from my mother dated January 26th, 1988:

My dear Kate,

How are you doing? The month of January is sailing past. Christmas seems a very long way away. I hope you and John enjoyed your break. It was pretty hectic and a long way to drive with two babies. It all seemed to pass like a dream for me, but at least we made it. Was it all worth it? Well, I think we have to be positive about it even if there are some regrets in our minds. Have your pigeon pair settled back into routine? How's Edward getting on now in nursery school?

Letter to my parents dated February 25, 1988:

Just a short note

1. *Re: April 20 – CDL in Geneva / ACL vacation.*

I'm away from April 12-15 and from April 17 (evening) to 20 (evening. I have a commitment in the office on April 21 for a workshop which I can't get out of, but could take Friday and Monday, April 25th, off.

2. *I have sent an order to Lands End and requested it to be sent to you. I didn't have room for more things and have ordered a light pink and light blue t-shirt for Beatrix and Edward respectively. According to size chart, Beatrix should be size 2, but I can hardly believe it. So before I*

order from them, can you look around for equivalent tops and shorts for Beatrix (83 cm tall / 32 or 33 inches) and Edward (100 cm tall / 39 inches) with similar prices to Lands End. Colours for Beatrix in order of preference: blue, red, pink. Colours for Edward: blue, yellow, read. And I will pay you.

No overalls please. They are awkward for potties. Apart from shorts and tops I don't think they need anything. Edward loves the crocodiles on Lacoste t-shirts, but I'm not paying over \$15 a shirt.

3. *Can you get cans of Scotchguard spray for sofas. My sofa covers were cleaned in July and I asked them to be sprayed with Scotchguard but if they were I don't see it. If you can, can you bring them over with you?*

We're going up to Crans tomorrow. I'm taking a days holiday because I've been off work with flu and had to cancel a course. So my weeks planned holiday is now taken up with the rescheduled course. The flat is being rented as of March 1st for 600.- a month, not including heating and charges. One problem less!! But I'm so glad we're keeping it. I'm glad you've deferred pay-back too. Thank you!

Looking forward to seeing you both in April. Hope the dates fit.

Family's thriving. Beatrix can now say "Ed-wa". Progress in leaps and bounds.

Letter to Jenny, a potential au pair girl, undated/ around February 1988:

Meyrin-Geneva

Thank you very much for your letter. Please excuse this photocopied part of my reply, but the response was greater than expected and I would like my letter to you to be complete, and therefore long. Being a working mother means I do not have a lot of time on my hands!

To tell you about the family – John, my husband, and I are both English. John's father is Belgian and he spent most of his life in Brussels. He speaks a little Flemish. I spent most of my life in Switzerland. So we are not 'really' English. However, at home English is the common language. We have a hotel business background, but have changed orientation. I work for Digital (DEC) as a skills and management trainer, i.e. I run seminars and course for Digital employees. John is working as a freelance photographer and should start his studies in psychology at Geneva University in October.

Edward, our eldest child, was born in December 1984. He spent his first year going to a day-care centre. He is sociable, extremely energetic, can be quite serious, but very affectionate. He is demanding. He goes to play school every day from 8:30 to 11:00 which keeps him busy and active. Edward is having problems coping with the mixture of French (at school) and English (at home) and does not yet speak clearly.

His sister, Beatrix, was born in August 1986 and was 8 months old when I went back to work. Her character is developing, slowing, into a strong, independent but adaptable child. She is very affectionate and very attached to me. Her speech is advanced and she is very clever with her hands.

As for our environment, we live on the outskirts of Geneva in Meyrin, in a large flat on the 9th floor of a 13-floor apartment block. On one side of the house there is the agricultural zone, bordering on France, and woods. It is not the countryside, but it is very practical for a busy family with two young children. The playschool is across the garden space. There is an outdoor swimming pool on one side and an indoor pool on the other. By bus it takes 15 minutes to the centre of Geneva. We also have a sailing boat on the lake and spend a lot of time on it. We have a flat near Crans-Montana, but we may rent it out; otherwise we use it on weekends.

About the job: until Beatrix is 2 ½ (next February) and can go to playschool at the same time as Edward, it's a five-day week, full-time job. The girl who works for us now starts at 7:30 a.m. and finished when I come home in the evening (18:00-18:15). However, I travel for my job and am away from home one week, i.e. four nights a month. During the time I'm away, it's more or less 24 hours a day – unless Beatrix has finished teething.

During the day you would be solely responsible for the children, their activities, their meals and their environment. Children have a short span of concentration (15 minutes approx.) and sometimes need help to find things to do. I agree that they should be left "alone" for an hour or two as well. They still sleep at lunch for one to two hours. Last summer they went for swimming lessons with the aupair girl. There are quite a lot of things to do in Geneva and you can easily take them on the bus.

About household duties: I would consider your room, shower-room and children's room to be taken care of by you, including your and the children's

laundry. The kitchen should also be cleaned after your and the children's breakfast and lunch. Either I or my husband cook supper in the evenings.

Babysitting duty: maybe once a month in the evening and one Saturday a month. Otherwise evenings and weekends (Sat. and Sun.) are your own time. There are quite a few evening schools in Geneva, and opportunities to meet other young people.

When? The girl who lives with us now would like to leave mid-May or end of May. She will have been with us for 13 months. May 21st would be a good date as I have 3 days off and could spend time with you.

Length? I would consider one year to be correct. We would apply for an au pair working permit, which is limited to 12 months.

Holidays: 2-3 in August or September. So you will be free then. And 10 days at Christmas time.

How much? 500.- a month, live-in, plus accident insurance.

If this sounds interesting to you, please let me know as soon as possible. My husband will be in Brussels from March 28 – April 1 to help his mother move. He would like to meet you. If you have any questions that need a quick reply our telephone number is 022 83.06.01 or at work 022 87.41.03. If you can't meet my husband I would like to talk to you, but send me your number so I can call you.

Letter from my mother dated May 15, 1988:

I gather Dad spoke to you on Friday. Sorry to hear you're feeling a bit sore from the mole removed. Very brave of you to do it, but I guess after the caesarian this must have seemed quite mild.

I keep thinking about your possible new home and pray that it will become a possibility, but if not this time there'll be another. (She explains about a company trip to New York for dinner). I really decided on the way home, I too am ready for retirement. Or perhaps I have never been a company wife.

Listening to the rubbish these younger people talked on the way home (we were in a mini-bus) and all laughing at one another's jokes, I found very boring. (Of course I'm not including my children of being involved in such chatter.)

Andrews repeatedly called to the back, "Lindley, stop playing with yourself – wake up" was the tone. I suppose it is something he had said to him frequently as a child. I just wonder who is the poor fish who will get shouted at on Dad's retirement.

Wasn't that great news about Matt. Sue is very nice, pretty and plucky. She doesn't make her disability more obvious than she need. She's got a massive chunk of ch... - and appears really chuffed she's landed B.B. It is really wonderful to know that they will have one another to share their lives. I don't think she'll let Matt watch terrible movies on Christmas Day!

Thank you both for a very lovely visit – it was so reassuring to find you calmer and more confident than at Christmas. You went through a very hard time and have come through shining. I feel you've grown in strength and love and the children too are so much more relaxed and contented. I was so pleased.

Letter from my brother, Matthew, dated June 6, 1988:

Here are your photos – hope they are ok. Sue and I went to Cornwall for 5 days after being in London. Mark and Meroulla were impressed to quote him! We're both pretty tired. I think it's partly due to the excitement of getting engaged and starting to house-hunt. We're looking for a 3 bedroomed bungalow but there are very few coming onto the market. I hope things are working out for you with this farmhouse or whatever! We've got 20th May booked for next year but may be changing it to the 6th May as numbers have gone up and we need a bigger reception room. It's a very nice hotel and it should be a good setting for the reception. Are you coming to England this summer? Love, Matt

Summer 1988

I took the family to New Jersey to spend two weeks. We spent some days at my parents house in Mahwah, then we went to the shore for a week where my sister and daughter, Esther, joined us, and then we had a few days in Philadelphia staying at my sister's. During this time or afterwards, my brother-in-law recommended that we read Gordon (1970) on parent effectiveness training. I read the book in French.

Letter from my brother, Matthew, dated August 15, 1988:

Sorry the card is so late – I got the date all wrong! Hope you had a good holiday in the States. Thanks for the card. Things are going reasonably well with us. No luck yet with selling my flat. We are looking into getting a new bungalow in a place called Congelton which is 10 miles south of here. It depends if it can be built/ finished by February 1989 otherwise it's back to the drawing board. Hope all is going well with your new home. I hope it will be accessible for Sue – we want to come and visit you.

We're going to Hall Cottage for bank holiday weekend. If it works out we'll spend our summer holiday there – well put it this way we'll spend the last two weeks of September there for a holiday. Got to get the beds downstairs!! Hope you are all well. Love, Matt and Sue

We bought a house in the countryside around this time. It was a small house with a barn attached, and our plan was to turn the barn into our home and rent out the house. We hoped that we would move in to the renovated barn by December 1987, but planning permission was delayed. The most memorable part was that we had no hot water heater for ten months. I heated large pots of water on the stove for the children's baths every evening. The barn house was finally completed in April 1989.

Round robin letter and enrolment for kindergarten at Satigny dated August 29, 1988:

The letter confirms that Edward has been enrolled for Monday, Tuesday and Friday mornings, and Beatrix for Mondays.

Letter to the kindergarten in Meyrin dated August 25, 1988, translated from French:

I regret to inform you that Edward will no longer be able to attend kindergarten because of transportation problems. I would like to thank you and Astrid for everything that you have given to Edward, assisting him in his development, during the past year.

Letter from my father dated October 22, 1988 from my sister's house in Merion:
Dear Kate,

The enclosed T-shirt acknowledges that you are a member of the exclusive Lindleygram club. This is in recognition of you having been privileged (you may not have thought so at the time) to have received several Lindleygrams. Other members include your Mother, Sister and Brothers, Klaus, David, Pierre, Malcolm Searle, Dick Feeny, Pat Ramirez and several other lay-abouts in Princeton labs. Your husband does not qualify for membership although he probably deserves to have received several Lindleygrams but did not in the cause of family unity! No grandchild qualifies either. Steve thinks he does but cannot produce the evidence! Being a member means that you have to be prepared to receive Lindleygrams in the future but gives you the right to send

Lindleygrams to any other member (e.g. MEL (Mark) but perhaps he has already received one or more from you?). The annual subscription is due on Dec. 25th.

We had a super holiday out West – saw so many mountains, canyons, etc. in beautiful weather. The West is so much nicer than the East, cleaner, less crowded, better climate and so on. We drove nearly 2000 miles in 9 days because distances are so enormous. We visited Disneyland and the Citrus Experiment Station in Riverside where I worked the year you were born. We stayed the weekend with Jan and Eric (Jan was the youngest Corner, sister of Peg) in Santa Barbara, which is a beautiful small town on the sea. Then a day and night in Las Vegas (\$10 lost in the slots) and back to the garbage state of New Jersey. The house closing is delayed until the 27th when we leave for London that night. I hope there are no hitches and that we get our money.

How are you all doing? Hope the building work is underway, the boat ship-shape again, and the hubby is studying hard. If not, I'll consider sending him a Lindleygram!

Esther is keeping us amused and busy. Charlotte is getting bigger but is in blooming health.

Chippy is no more – a very sad day when we took her to the vet, but it was the best thing for her. No suffering or pain, and we all have memories of great times with her.

Great news about the sandwich bar in Cambridge – we will see C & L more often too as a result.

We hope to come out for a bit of skiing in the Geneva area in January. When is low season? Get us a few leaflets of places we might go to, could you please?

We'll call you when we are back at Castle Rising. Love to all. Yours ever, Dad

Main breadwinner – October 1988

Letter to my parents at Hall Cottage, Castle Rising, from our house in Peney-Dessous, dated October 16, 1988:

Welcome Home!

I don't know how far I'll get with this. Fi and Edward are busy painting you a picture each. I have tried to explain that you have left 'Merica and gone to live in England. Edward would like to know if you live with Luke. John is making a model Avro Lancaster. Hubert is asleep on the living room floor and Dimitri, his companion-cum-nurse, is watching TV.

We have just replanted the eight trees of the front in the middle of the garden so we can double the parking space (although the parking space is a sandpile). Yesterday we finished plastering the upper part of the farm and John will dismantle the wooden floorboards this week. By the way, CDL, the Round-Up took 3 weeks to really kill, and underneath the green grass is pushing up. At 66.- a bottle, I think it could be more effective. I did part of the end of the garden to test it out. I redug the area where it worked and removed the strips of metal planted down in the ground. We've got rid of the green fencing, the metal posts and the roof tiles planted down the side of the path. John sees the progress and is now busy helping me a lot. Especially as we won't be able to start the building until Jan. 15th! The architect had to redraw the plans because the authorities didn't like the windows. He says we should be able to move in by the latest on April 1st.

John starts courses on October 24th and has got all his papers. He has two full days and three half-days and not a hope in hell in getting work done at home. Birgitta got an aupair girl! She's going to work part-time in a wool-shop teaching people how to use the fancy knitting machines, like Mrs. Rowe did with Bernina, I guess. Anyway they found a real pearl. She goes out every night and says she doesn't have to lift a finger on the weekends cause she's off! Jenny says she feels about 16 years old next to her, and so John told her better that! Jenny is fine, our angel. John is going to persuade her to stay another year. Hubert has had his right thumb partially removed and is supposed to be taking it easy. He's definitely weaker than before, but swears he'll have time to rest elsewhere. We haven't seen him for ages. Betty's coming for Xmas. That should be fun!

Trying to write a letter is definitely an endurance test around here.

I've had Mark on the phone a couple of times and I had a long chat with Matt while he was at Castle Rising (I paid for it.) Getting to the wedding is not going to be easy. John will be a month away from exams and doesn't want to take time off. (This is a first year student!) I have thought about driving over on my own. Maybe you could drive back with me?! John has offered to babysit the kids and let me come over for the weekend. I did say to Matt that John might not make it and he sounded very disappointed. I know we're a long way away, but I'm supposed to plan 1989 in November I'll be planning my courses as well, but I'm looking around for a new job within Digital, within training, but I don't want to have to deliver only. I want to get into course design, which will still mean a lot of course delivery, but less. Judith, my boss, has told me that she cannot reduce the number of delivery days and she doesn't seem keen to let me do project work and design because that's what she likes to do. We are moving offices in December and Remy, Super Swiss, has decided that we will have the Office of the Future: no individual office space, no assigned desks, but different areas for the varied tasks. If you want to use the computer to do your mail, you sit at "a" desk. If you want to read, you sit in the easy chairs in the reading corner. If you want to talk or meet someone to discuss a project, you go to the "meeting room" (proposed – a garden swing with room for four). If you want to work quietly, you go to a "box" and close yourself in. Your telephone is cordless and you can take it to the loo so you don't miss any important calls!!

It's harder to write now that Hubert is awake and demanding attention. John doesn't look like he wants to move either so I better look after supper. He's found a new recipe for bread. It's really delicious. The neighbors are impressed.

Welcome "home" to Castle Rising. It's strange writing to you at your new address. We'll be on the phone soon. Digital appreciates your moving, the phone bill will decrease. Fifi and Edward send their love. They were sad to hear about Chippy. So we had a long talk about death and heaven. Chippy is now a doggy angel. We saw a super little pussycat yesterday, a real cutie. Next year. Lots of love and bon courage. Save sheets, pillows, blankets and saucepans for me! Kate

B. Chapter 4: Edward's school years from 1989 to 2000

Edward became eligible for school in 1989. In the springtime I went to the enrolment day at the local primary school and met Ms. B., who talked to me the way primary school teachers talk to parents whose children are going to attend school for the first time. I remember her telling me that if Edward were very lucky he would be in her class. I hoped that he wouldn't. I hoped that he wouldn't want to like this teacher.

Living out in the countryside, three kilometers from the school in the municipality, proved to be an obstacle. The school system allowed children to come home from lunch each day during a break of at least an hour and a half. The booklet *Ecole Primaire* (Primary School) from the Geneva department of public instruction (DIP) sent to all parents, in 1993, states on page 14 that class starts at 7:55 and finishes between 15:05 and 15:35, depending on the lunch break. Lunch break is either one and a half hours, one and three quarters hour or two hours, depending on the local school. The pupils (page 16) have Wednesdays off and every other Saturday morning.. Until 1991 the children had school every Saturday morning.

I rescinded Edward's enrolment for the local school in a letter to the school inspector, Mr. P., on June 15, 1989, translated from French:

I would like to withdraw my son's enrolment from the school. I cannot ensure his presence for the following reasons:

Our current situation is that I work and my husband is a student. We have an au pair girl who looks after the two children. We have one car for economic and ecological reasons, and because of the lack of public transportation we are obliged to travel into town by car. It is therefore impossible to take and collect the children four times a day.

The school is three kilometers from our home. I asked Mrs. Notz, the inspector for the schools in the neighboring village, if Edward could attend this school. She hasn't refused, but she did say that I would have to ask the mayor of this village. My au pair girl could easily take the children to school by foot to the other village. There is no pavement between our village and the school.

I am therefore obliged to purchase a second car, and thereby contribute to the pollution of the Geneva air, or find a more appropriate solution for a working mother.

My solution is to withdraw Edward from public school this year.

I have heard that there are other mothers in our village in a similar situation.

We cannot count on the mothers who don't work and who take their children to school by car. If there is a possibility to organize a school bus, please let me know.

Jenny left in the summer of 1989 after 13 months with us. We decided to enroll the two children at the Sainte Marie private day school in Geneva, and forgo having an au pair girl. John could take care of the children during school vacation. The yearly school fees for the two were not much higher than having an au pair girl.

I wrote to the director, Sister Andrée, on August 28, 1989:

Is it possible to put the two children in the after-school class after the autumn vacation? As their rhythm will be changing, I don't want their days to be too long at the start. My husband agrees to pick them up earlier.

Beatrix did well in kindergarten and had mastered French by December. However Edward was having difficulty in the class he was in. It was decided that as he hadn't attended kindergarten for over a year, he would do better in a lower grade. I was told that he was having difficulty remaining seated, and often asked to be excused to go to the toilet.

1990, a difficult year

In April 1990 I wrote to my family:

Edward is doing badly at school with his hysterical Rumanian teacher. He really has had a hard time so after Easter he will change schools and go to the local school.

A new au pair girl, Ieke, (pronounced A-kay) starts on Easter Monday.

Selection criteria were established by Fi and Edward. Fi wanted a girl with long hair in a ponytail and Edward wanted "big breasts".

In May, I wrote: *Ieke is a wonderful bit of good news. The children are quite happy although we are going through the “transition” period: Edward often in tears when I leave, no napping, up at 6:15 a.m. and dressed. I took a couple of afternoons off and took Ieke all over so she knows how to win their hearts.*

At the end of 1990, I wrote to my family:

We also realized that having an au pair girl was easier than racing to and fro from a private day school, so at Easter time we put Edward into the local, public school and bought a second car for the au pair. Fifi (or Beatrix) started school in September and both of them are making progress in leaps and bounds, and can now swear in French. What a surprise! They also learnt to swim like fish, and Edward is also skiing down the mountains with Mother shouting, “snow-plough” behind him.

The other day he played Daddy and put me to bed, tucked me up and cooked me supper! I was really happy. I think we’ve succeeded in showing our kids that the role of nurturing parent is interchangeable! Long live Elisabeth Badinter and phooey on Sigmund Freud! We’re hoping that his fingernails will reappear after the change of schools – otherwise we’ll be in for family analysis.

Last night they tried to swing on the curtain rail and nearly broke the intact Chinese vase. Last week Edward stood on the window sill of his bedroom on the first floor, and closed the window – he was outside!

John has gone off to the boat with an assistant professor of the Psychology Faculty to take about experimental psychology and clean the boat up. It’s the latter part that I’m glad to have escaped. I can doze quite easily while listening to intense discussions of experimental psychology. It comes quite naturally.

In April, I wrote: *I’ve also enrolled at Geneva university to take a masters degree in Educational Sciences. I’ll do each year in 2 years which will mean four hours a week of class. I passed the French exam last week and now have to have an interview. It has been said to me that what I do within Digital is at the avant-garde of adult education, but I think a little theoretical background could help.*

In May, I wrote: *The good news is that I have been accepted at Université de Genève, starting October 1990 as a student of the Faculté des sciences de l'éducation (Educational sciences). I have a really heavy program.*

In October I wrote: *I am starting university as well at the end of the month. I will attend courses two afternoons a week in educational sciences. I have to keep up with this scientific man of mine.*

I'm working with a psychologist from Sheffield on teaching behaviours as a project which is super interesting. I'm going to attend a course of hers in Sheffield from July 17-20. I've even got John to sign up for it too so we'll spend two weeks after that in Castle Rising. So Ieke and kids will stay there while we're in Sheffield.

In October I wrote: *I also managed a project to understand what makes excellent trainers excellent which cost Digital about a hundred thousand dollars. We used behavioural analysis methodology, developed by Neil Rackham, formerly of Huthwaithe Research Group, and Peter Honey. Neil was the founder of the SPIN sales methodology. I worked with Rose Evison who worked with Neil many years ago. It was also really interesting and now I am fighting to implement a coaching package in Digital for training trainers.*

In April, I wrote: *We moved in to the new house 3 weeks ago. It's small, but lovely to be in a nice house with hot water, heating and a dishwasher! The terrace is nearly finished and the summer house is next on the list to be done.*

Edward started school in Ms. P.'s class on April 23.

An extract from a letter to my friend, Stefana, on August 6, 1990:

"THANKS" so much for your card. It made me laugh and seems to reconfirm that everyone does think that I am such a gay (in the old-fashioned sense of the word, please!), funny person and I had forgotten that, for some time, which most probably accounts for the dreary fact-filled, impersonal letters that have been crawling out from under my fingers for about the past 18 months. Is there a link between that and the building of my house – aha! I think so. It is now over and I relish being able to laugh again.

I was in England for three weeks ... dying in the English heat of the 30's on the beaches of Norfolk. You know, I mean, you may not know that having children is not what it's made out to be? Do you? It may have been the "done thing", but it makes you wonder why you did it? Or do you dream of spending your holidays running a 24-hour child-care service, doing everything you don't really want to do, but because you are one of those strange people called a MOTHER you don't dare own up to not wanting to????

A very good friend⁴³ said when Edward was about two weeks old in reply to me saying, "this is a bit strange and new to me, but surely I will get used to it!", he said and, what words of wisdom they were, "YOU NEVER GET REALLY USED TO BEING A MOTHER". So I went around asking people, especially the women, whether they really thought of themselves as "mothers", but they saw themselves rather as being labeled by others. I will now request that I am not labeled MOTHER, anything else, even OLD BAG would be preferable and would maybe get me out of going to the beach for two weeks a year to dig sandcastles, have sand thrown at me, eat sandy sandwiches, be jumped on while snoozing (33 and snoozing after lunch!!!) and then being told I am méchante (nasty) because I will not spend a fortune on Pzazz's and other interesting-looking objects that go by the name of ice-cream.

Oh, Stef, I do long for the days when we hung out, smoked cigarettes, talked about all kinds of things, drank a little wine, danced at the Darling, and got up in the morning when we felt like it.

Letter from the school inspector, Mr. P., on August 31, 1990, translated from French:

Thank you for your letter of August 27. It puts me in an embarrassing situation, you know, because school on Saturday is very delicate subject. No matter what the future perspective is, my role consists in making sure that the current rule is respected. I have no objection granting a free Saturday when a family has to face exceptional circumstances. However, what I believe you are requesting is every Saturday off for four months. If this is the case, I have to give you a negative answer. I am not refusing to take into account your particular family

⁴³ Richard Frost, the Catholic priest, who was Edward's god-father. Richard passed away in 1999.

situation. I will grant you one Saturday off per month, as a real exception. I would also like to make you attentive that other families are in similar situations and Yverdon is only one hour away from Geneva. Persuaded that you will understand the above reasons, I remain ...

A round robin letter from the union of schoolteachers early October, 1990, translated from French:

You most probably have heard from the media that the public services are preparing a strike for October 10. We have decided to support our colleagues to express our solidarity, to support those who are affected by the recent restrictions, and to refuse the suppression of the additional benefit, which represents a 3% decrease for all public service employees. We inform you of this strike ahead of time so that you can take measures to keep your children at home. If you cannot, please note that your children will be welcomed at school by the teachers.

Letter from the mayor's office on October 9, 1990, translated from French:

Concerning the schoolteachers' strike of October 10, we regret the teachers' decision to strike because we consider the duty of teachers is to teach and to ensure the development of the children. The mayor's office notes that the schoolteachers are well paid in comparison with the private sector. The mayor's office is also surprised at the discretion of the parents' association. They could have made known their disapproval of the teachers' decision. This situation can only deteriorate the confidence and the relationship between the teachers and the municipal authorities. The mayor's office also regrets the lack of official information from the Geneva department of public instruction to the municipalities of Geneva.

John got a job in the summer of 1990. I wrote to my friend, Mark, on October 9, 1990:

Anyway I realized during my summer vacation that I have been a pretty dreary person for the last year and a half – mainly to do with building a house and being on the brink of bankruptcy constantly. I'm still waiting for the bank to come and take the house away, but at least I have hot running water and heating now. If only I could find out how to put it on because John is living 85 kilometers away at the moment and I don't know all these technical details. John is trying to avoid bankruptcy by taking on a summer job. Well, what would

you expect a psychology student to do during the summer? Yes, you are right. He is managing the Grand Hotel des Bains in Yverdon

So John is there seven days a week, while I vacation in my new house with kids and au pair girl. Then I join him on the weekend in our “little place in the mountains” (Grand Hotel) where I do not have to wash, iron, cook, clean, fill the dishwasher, empty the dishwasher, empty the cat’s litter tray, garden, and all the other fun things that we get to do when we are not working. Life is starting to be kind to me.

Tomorrow we celebrate ten years of being in love, or being together. Maybe being together is better because we have not always being in love. In fact we have had two major split-ups, both of which lasted about half an hour, because we were too scared. But up until the actual “we’re splitting” it was really shitty. I hope you two are happily together again.

Do you know what Co-counselling is? If not, I will send you a book about it. It is a wonderful way of discharging those emotions that block us from moving forward. I now have permission to shout and rip up cardboard boxes when I am angry.

I find children quite a challenge. I find au pair girls and school teachers an even bigger challenge. Edward, nearly six, is seeing a pediatric psychologist right now because he is having difficulties relating to groups of people he likes. It’s ok when he doesn’t like them, but as soon as he likes them, he gets hyper-active which drives everyone away. It gets pretty drastic when it’s with family because then everyone starts telling “Little sister Kate” how to deal with her children, which blocks little Kate. So Kate goes off and does a co-counselling session with John. Oh, families and how to survive them. Talk to John Cleese about that, or read his book⁴⁴.

Postcard from Ieke, Edward and Beatrix on October 23, 1990:

It’s nice here but we miss you and we love you, Edward and Beatrix

⁴⁴ Skynner, R. and Cleese, J. (1983) *Families and How to survive them*. London, UK: Methuen.

Letter to my parents on October 27, 1990:

"It's Saturday – it must be Yverdon" The kids stayed the whole past week in Yverdon with Ieke. So – university starts on Monday – so I get two afternoons a week off from work to do some mind-stretching activity. At least I hope it will be. I'm worried that I've set my expectations too high!

I've been told by Digital that I can go to Cardiff from Jan. 3-5 to attend the Occupational Psychologists Conference and present with Rose Evison the research we did on trainers behaviours in course delivery. Work is going well. After the research project nothing will be hard slog again – or so it seems. But I am going to be very strong-minded if I don't want to get into the same situation again ... cause there are other extra projects I could work on ...

John's really tired, but I bully him around on the weekends and get him to take a nap and a walk in the fresh air. Doesn't stop him from working 14 hours a day, but makes him more human while I'm here.

Letter from my sister, Charlotte, on October 27, 1990:

Congratulations John on the job. It must be great to know you are so appreciated to be given this opportunity. However it must be hard on Kate to be without adult company 5 days a week!

Letter from the school inspector on October 31, 1990, translated from French:
I have just heard from Ms. P. that your son, Edward, has been absent recently. It seems that a written excuse is given each time, however they are always for Saturdays. You wrote to me about this on August 27, and I answered that we could consider some flexibility, but I also fixed a limit. You can understand that, within this context, we question the authenticity of the motifs given. Before there is further misunderstanding or bad feeling in the classroom, I am asking you to scrupulously respect the agreement of one Saturday per month.

Letter from John to Mr. P., the school inspector on November 2, 1990, translated from French:

It seems that your administration recognizes the right of parents of young children to judge their physical ability to attend school for short periods. I don't want to start playing with words, but in our case Edward has suffered enormously from the separation caused by my work in Yverdon. We have judge that his state did not allow him to follow his classes productively. Our son's

psychological health counts for us as much as his physical health, and we do not wish to put this in danger.

The problem will resolve itself as I will be in Geneva three days a week starting next week. Edward will follow his classes, which he appreciates a lot, on Saturday mornings. We have also agreed with the SMP (Service medico-pédagogique – the Medical-Pedagogical Service) that they will offer him help so that he can confront these small difficulties with more assurance.

Letter from my aunt, Auntie Hennie, on November 12, 1990:

Your Mum told me how well John was doing at the hotel, really pulling it round and making it run efficiently. I hope he is enjoying it and won't wear himself to a frazzle. You need to enjoy a bit of time off too!

How are your studies going? If you are finding them really interesting then it isn't such hard work.

Letter from my sister, Charlotte, on November 30, 1990:

Thank you for your letter and of course I will keep your confidence. It must have been quite painful to write, because writing seems so final. It must be because you can always read it whereas spoken words are often forgotten. Anyway I'm truly glad for all of you that you all get the help you need. It's so difficult to raise children - and I believe that it is because of their own personalities. And then we, as parents, come along with our own baggage and imprinting from our own individual upbringing and that it's so easy to want to do the right thing but are unable to because of the child's own personality and two individual divergent parents. I do not mean to suggest that it's your fault – or impart blame – the situation was and then you have had the courage to search further and find solutions. That's really the hardest and most painful part. Areyh Maidenbaum said to me today it's just too bad that all our personal growth comes out of such suffering. But then of course he and Steve (and John) would be out of a job then if there was no suffering!!

When I watch Esther and Lydia and see the different personalities I just know that Lydia is easier. She's just more accepting, less demanding. She has a sweetness about her. I can discipline her and she'll just cry and cry without my raising my voice, whereas Esther you can scream, hit, rant, rave, threaten, punish and it seems to make no impression. I do have a suspicion that inside somewhere it is making a dent and I'll pay for it someday. Larry Shapiro, a

friend of ours, who is also a child psychologist said at about age 5 things should get better – I'll hold all judgment on Esther.

So I guess what I'm also realizing is that I'm sure Mummy dealt with us as we deal with our children, responding to their individual personalities, and I suspect that is why we both feel such inequality in our experiences of mother and Mummy. I think at least we have searched out help to deal with ourselves and our relationships and that in the long run will help our children. So out of all the pain and suffering will come great good for you all together and individually and that's great. And I think at some point we have to stop feeling guilty but it's easier said than done.

I'm re-reading your letter and got to the part about being "at home" with Mum and Dad and bringing out reminders of us and our relationships or non-relationships. I think it's hard not to feel like a child again. I've talked to others and they have had similar experiences. Like Steve says I have this romantic idea we'll all get together and it will be fantastic and it's not at all. It becomes 4 adults and their families under one roof becoming children again in front of Mum and Dad. And then we regress to those roles which is so hard not to do, then we get in trouble. What seems to work for me though is to expect it and try to trouble-shoot before, but it obviously didn't work this summer!!

I'm glad you wrote to me and I admire and respect you and hope that I don't fall into the trap again of putting you down to feel superior. I'm not sure what our plans will be next summer but should they coincide we can start being more conscious and working on it.

May I say one more thing at some point if you need additional help maybe a family therapist could help you all out? I think they do wonders at helping everyone and you feel less isolated and ultimately less responsible because the treatment is geared to the family as a group rather than at the individuals. I'm also reluctant to write this as I don't want you to feel I'm making judgments or being superior or telling you what to do or anything .

It seems that what I hear from Mum John is doing a fantastic job at the hotel. It must be infinitely more stressful now that he goes to Geneva for 3 days and then back to the hotel. But the money must be great.

Letter from our friend, Jenny, on December 4, 1990:

How are Edward and Fifi doing? You never call her Fifi anymore. How is Edward doing with his speaking classes? I'd really like to see them again. It has already been such a long time.

1991, the year our marriage was on the rocks

Letter to my friends and family early 1991:

1990 was the Difficult Year. We moved into our new house, or the renovated barn, but the rising mortgage rates and the soaring building costs sort of removed the pleasure of running hot water, heating and a home-made house. We did have some moments of pure elation with John completing his "demi-licence" (something like a BA, but he still has two years for the MA) with the best results of his year. I got a promotion, started studying part-time Educational Sciences and presented a research paper on trainer behaviors at the British Occupational Psychologists Conference in Cardiff. We also got into Co-Counselling and attended a course on it in Sheffield together in the summer. We had a new addition to the family (you've got to be kidding – two kids are all we need..) in the shape of a black cat called Max who is a dream come true for me. He is already the fattest in the neighbourhood and is patient with the tail-pulling he gets from the children.

John took on a "summer job" which has just finished; managing the Grand Hotel des Bains in Yverdon. It was quite an experience to be thrown back into the hotel business and memories of Morocco came flooding back, although I'd never been the "manager's wife"...

Letter from the school inspector to me on January 14, 1991, translated from French:

You most probably remember the different exchanges of letters that we have had since the autumn. Both Ms. P. and Ms. M. have drawn my attention to the absences of Beatrix and Edward, that they have been more regular than was agreed. I see that the current situation is abnormal.

If the school has to react, it is not to be upset, but to ensure the best chances of success for Beatrix and Edward. I would like to meet you on Friday, January 25, at 17:00 at the primary school to discuss this.

Letter from my father to John on February 14, 1991:

Dear John. You have been very much in my thoughts since we heard of your problems. Please don't think that I am on Kate's side in this business but am concerned equally for your well-being. There is nothing unusual in a marriage relationship having periods of stress. That of Anne and myself certainly has and we were fortunate enough to get professional advice from various priests at critical times. The adjustments to retirement and our changed lives together has been and still is difficult. One can only take one day at a time and try to live that day in harmony. For me personally, trying to live a Christian life is all important but that is not for everyone.

I have been happy to learn that you are receiving professional help since that shows you are determined to resolve your problems and that you are not walking away from them. I am concerned at the effect a breakdown will have on you and on Kate and on the children. The only help I can give is by prayer since I know that prayer works miracles all the time. Yours, Chris

Round robin letter from the gymnastic association on March 31, 1991:
translated from French:

On April 11, there will be a gymnastic contest, at 14:00 in the Satigny gym. Please could you confirm that your son will take part by returning the attached form.

Letter from my mother on April 24, 1991:

It was good chatting to you again. If I was a bit stilted towards the end, our house guest came in and sat down for his breakfast, all ears.

After I was chatting to you, the thought came to me that perhaps it doesn't help you to compare notes on feelings and behaviour in certain situations – inherited qualities – er unqualities! Perhaps you can tell me sometime. It is difficult for me to know where I stand sometimes as Mum and friend, and really only you can help me – to help me sort out my doubts. As I have no role model, I wonder how much sharing you want from me, or are you happier if I am a listener? I do like it when you confide – talk and share – because I feel it develops the friendship side of our relationship, but sometimes I feel children don't want to share the troubles or even know about them – perhaps from a security point of view (and no one gets through life without troubles, but we can and do live through them and grow) – so perhaps you might tell me your thoughts on this –

please don't be afraid to tell me, done with kindness it can only help our friendship grow.

I think of you lots and pray that each day you'll find peace and joy and fulfillment, between the trails. Beatrix asked when were we coming to see you. Perhaps you'll be coming to us first. I don't feel I've been much practical help these last months. I've really left it in your court to ask. I miss you all.

Letter from my father dated May 13, 1991, including a home-made card:
Cartoon of a couple sitting in bed naked, with the sheets pulled up to their shoulders. The man looks embarrassed and has his hands under the sheets. The woman looks angry, with her arms crossed. The caption reads, "Good grief, Gerald, it's 11 May and the sap still hasn't risen!". My father wrote: *This is a sequel to the old Norfolk saying, "Hooray, hooray, for the 1st of May, hedgerow*

...

Glad to hear that the sun is shining over Peney-Dessous again and long may it continue.

Letter to my brothers and sister (and copy to my father) about my mother's 60th birthday party on May 19, 1991:

First of all, I should inform you that John and I have decided to stay together and are very happy about our decision.

Extract from my personal diary dated May 21, 1991:

I have finally bought my notebook to record my thoughts, my achievements, to help clear the confusion and bring clarity, shining bright, to my darkness.

It is difficult to know where to begin. I'll start from today.

- *The energy I put into pleasing men.*
- *The lack of recognition I receive in return.*
- *The emotionless statements they make and my emotional reaction to them.*
- *Feeling powerless.*

Letter to my parents on June 2, 1991:

In reply to your remark of "has the sap risen?" I would like to quote a paragraph from the book BrainSex, by Anne Moir and David Jessel, which states that women and men have different brains and consequently that women just make better mothers than men and that men have to learn to be parents

whereas mothers have it the knack of parenting naturally. Men can then continue to put all the responsibility where they feel it should lie.

Anyway for the quote: "In men, testosterone secretion has a rhythm, reaching peaks six or seven times a day. It is high in the morning, and on average 25% lower in the evening. During sleep, high testosterone levels correspond with 'active' sleep and rapid eye movements. Testosterone levels also change with the season. In the spring the level is at its lowest. The high point comes in early autumn. We may have to rewrite poetry books, and abandon all those metaphors about the sexual sap rising with the greening of the year. But then, a lot of sexual folklore is overdue for revision." Page 104, paperback version, Mandarin.

The children are doing fine with Bridie. She has been put to the hard test by Edward and still likes him after three weeks so he has given her the pass mark. He has calmed down a lot. We now have a rhythm for the evenings: Bridie feeds them high tea at 5 p.m. and then when we get back, I put them in their bath, and get them ready for bed and lights-out at 7:30 p.m. by which time John has prepared the meal for the adults. It is rather nice, especially as we can eat out now in the evenings. I don't have to spend my weekends cleaning now so I can spend more time at the swimming pool, at McDonalds and doing kiddie things. John is studying hard for his exams. He may already start working at the University in September. In any case he is accepted as an assistant-professor starting October 1992.

I have two papers to give in by the end of the month and I will have obtained my four credits for the year. I have a paper to give in for October for another credit, but I have five books to read on institutional psychology and don't have time for the summer session. I am going to apply to Open University as they are coming to Geneva for the Feb. – Oct. 92 university year. It would be just as good for me to have a bachelors as having a masters so I am going to see if I can transfer. I really do love the studies, not so much the studying. But I am also going to start looking for a new job, within Digital and outside, because I have had it working for these bloody Swiss who pretend to be Anglo-Saxon. If I can get the project management for the project I started with Rose on training trainers, then I will work about half-time for a British twit which is still a damn sight better than working for a Swiss-German.

We have nearly sold the old house to Anne. ... She has a little five-and-a-half-year old boy, Lucas, who loves being with Edward. She is getting a mortgage with her pension plan which takes more time than with a bank, but hopes to have it by mid-June and would like to move in by the end of the month. Lucas will be looked after by Bridie which will increase her salary. We will celebrate when we sign ... with you as well.

By the way I never replied to a certain letter about a certain amount of money. I think we had plan it to be part of my inheritance as I cannot see how I could pay you back before Dr. John has a chair in Entrepreneurial Psychology at some great university.

*Extract from my personal diary dated June 5th, 1991, 5:45 a.m.:
Notes over the week. I had my job review on Tuesday, May 28th.
My strengths are: initiative, creativity, adaptability, flexibility
Weaknesses: organizational sensitivity, problem analysis in complex situations.
Feedback: Great courses – great delivery, flexible approach, etc. but outside the courses the same approach disappears. Daniel and Marie⁴⁵ wonder “how does she do it?”*

Daniel said that I was a zero for the new hire integration project. Marie said that I don't listen.

What I said to Judith⁴⁶ : this job review is important for me for one thing: to get feedback from you. I am at the point where I don't need a job plan. I do what I have to do, you give me feedback, we work well together. If going through a detailed review will increase the percentage by 5-10% I'll do it, but I think not.

Two points of concern:

- 1. the feedback is conflicting*
 - a. you're the best in the group*
 - b. if it wasn't for me you would have been fired (Daniel and Marie approved my promotion, so what is going on?)*

⁴⁵ Daniel was the HR manager of the Swiss-French region, and Marie was the HR manager of the European HQ of Digital Equipment Corporation.

⁴⁶ Judith was my direct manager.

2. *the ethical problem of the difference in salary between Robert⁴⁷ and myself*

An extract from my personal diary dated June 4:

It just overwhelms me to be assertive. It seems like three situations have reared their ugly heads in close succession to test me. Hanging over my head is a meeting with Daniel to talk about his feedback. I feel that I'm coping with the behaviour side but it's costing me so much on the emotional side in energy. I have dreams of fear, of Edward falling or jumping over the gallery on the 4th floor of the university. I feel like I'm jumping off the 4th floor into an abyss. I don't know the consequences of my actions. How far down does the abyss go? Will I die when I hit the ground? Right now I think I will. I cannot respect myself if I do not stand up for what I consider to be right and just. If I don't respect myself, who will respect me?

Affirmation:

I'm Kate, I have beautiful curly hair, I look great in blue jeans or Cardin suits, with or without make-up. I am skilled at asserting myself and my views on what is right and just. I will stand up and demand respect for myself and my views.

Extract from my personal diary on June 6, 1991:

So here it goes again. I'm having a hard time. I go to John for support who says, "you're such a unhappy, dissatisfied person. You should do this, this and this, go and see the company president and tell him what it is like". The same day he says, "oh, I should not be telling you what to do". Again I need to discharge in order to move on and he goes off to Dr. R⁴⁸. and we're back to where we started. He paints this black picture of us having different needs and not wanting to compromise, make concessions.

I'm so pissed off with

- *him for always hitting me back after I've asked for emotional support*
- *him thinking that he's responsible for my happiness and unhappiness*
- *him for trying to get us to talk about this before I've made enough progress*

⁴⁷ Robert was my work colleague, who was hired at 30% more salary than me, and was less experienced. I was supposed to train him.

⁴⁸ Dr. R. was our couple therapist from January to November 1991.

- *him for saying he will find recognition outside but he needs unconditional support*
- *him for having double standards about his needs – somebody to look after him, be his father (financial support) and his mother (emotional support).*

I place value on giving each other listening time for work problems, each individual has the responsibility for own happiness, each one decides when ready to talk, not forced, respect for what the other wants to do in life, including being involved in the big decisions of each other.

I'm so fucking angry.

Extract from my personal diary dated June 9, 1991:

After my writing I said to John that I would cancel our meeting together with Dr. R. because he (John) does not need the stress of putting our relationship in doubt just before the exams. He agreed.

HOW VERY CLEVER OF ME TO OBTAIN WHAT I WANT WITHOUT SHOWING MY ANGER.

I should celebrate my skill, my skill in what? My skill in keeping my cool. But thinking about it – 3 days later I can feel the anger mounting again. He seems to have taken the decision to join Professor M. 's group and be an assistant-professor at the glorious salary of 3'600 SFr /month. He has made remarks like, "it would make me really happy if you could work freelance ... " I would like him to outline the future as he sees it to me. He obviously has schemes to bring in money, but I only hear vague mentions. He said the other day that he needs me to believe unconditionally in him. Part of the reason he went elsewhere to talk was because I had stopped listening ... which is true, as I told him.

I stopped believing that he was going to be a success in life cause he didn't make a success out of the house, his job to some extent (more due to the fact that I felt he should have got angry with Mrs. S., his former employer). With the messages from Mum and Dad in my head I felt that I was married to someone who wasn't capable of looking after me and the children and he went down in my esteem.

So I stopped listening because I can only respect people if they are capable and competent. I enjoy asking John about psychology because he is competent there. I can see he has made progress since his therapy in taking control of some things, which I appreciate.

I want to hear from him how he sees our roles because I see it right now that he is demanding EVERYTHING, i.e. everything that I can negatively envisage. That is an assumption. So it is, i.e. the miscommunication is becoming clearer. He wants my respect. For my respect, he has to be capable and competent, plus we both want him to contribute financially to the upkeep. For him to be capable and competent it must be in the domain of psychology which means becoming an assistant-professor.

The thing that bugs me most is that his income will not ensure the upkeep of the family and that his choice of career plan limits mine to that of principal breadwinner, which limits me to doing my studies over a longer period.

Ah, how putting it down on paper helps me become clear.

If I go back to our original agreement, which is the only agreement I have made, then I have one more year of full support to carry through. I must keep to my word. In a year's time – what would I like to do? Which in any case is the question because until I know that, I cannot ask for anything.

In a year's time I will be 35, John 39, Edward 7 1/2, Beatrix nearly 6. I would like to cut down on my working time to increase my study time. I will have 12 credits out of 18 because this coming year (91/92) I will take only three courses. Year 92/93 I would finish my demi-licence which means I would do the last six courses at that point in time. I would like to work three days a week, do 12 hours of university and have a half-day extra for the kids and the home. At my current salary of 7'200.-, 60% would mean that I would have an income of 4'320 a month. Our costs are around 9'000.- a month so I would be contributing half. I will contribute half for the continuation of my study time (?). If I had one year to finish my demi-licence, I could use three years to do the rest.

If John works for 5 years as assistant-professor starting 1992 then he will get his doctorate in 1997, at which point he will want to leave Geneva.

About work:

I don't want to stop working completely.

*I don't think it's ethically right for a woman to count on a man as a meal ticket
(Neither should a woman be a meal ticket for a man, Kate!)*

*I have the same right to study as John has, and the same right to decide on a
career plan.*

*I don't wish to continue being the main contributor, neither do I wish to be tied
to Digital.*

Extract from my personal diary dated June 17, 1991:

I went to see Dr. R., looking forward to seeing him.

*I have had two new experiences which, although I'm somewhat proud of, leave
me feeling rather ashamed, or uncomfortable.*

1. me telling John we would not go together to Dr. R.

*2. on the evening we went to see the film The Field, I told John that I didn't
want him to work during the vacation but because I wanted to be with him
(instead of "it's not fair, why should I look after the kids all alone?", etc.*

*Dr. R. said/replied to my question of honesty that my actions were honest in the
sense that they helped safeguard the harmony of our couple.*

Extract from my personal diary dated July 12, 1991:

*On Monday at Dr. R.'s I talked a lot about John and discovered some sadness
about the lack of birthday gifts. Reading Watzlawick this morning I came across
the 'paradoxe du type "sois spontané"'. "C'est l'un des inconvénients de la
communication humaine que la satisfaction spontanée d'un besoin ne puisse
être obtenue d'une autre personne sans créer cette sorte de paradoxe voué à
l'échec ».*

Extract from my personal diary dated July 26, 1991:

It's been a shitty day.

There will be more lay-offs at work.

The politics stink.

Management can't take a decision.

The children are hot, sticky, scared of the first day of school.

Husband's not talking.

Letter from my father about the organization of Mum's 60th birthday celebration
on August 4th on June 17, 1991:

*Finally we are very happy to learn that you and John will stick it out a bit longer together. Everything worthwhile in this life takes a lot of hard work, marriage especially. For two people like Kate and John who have had something going for 10 years, it makes no sense to throw in the sponge now, particularly since your kids need both of you under the same roof. I am arranging to take a few minutes each day of your stay from mowing, painting, hovering, washing up, and beating my wife. In fact I might beat my 1990 record and come to the beach twice. Love, Dad
PS I will have great difficulty to call your husband, "professor". Give me a break!*

Letter from my mother mid August 1991:

I'd like to thank you for all your hard work – you and John – that helped to make August 4th such a wonderful day. The memory lingers still and will for a long time. I had a very happy day. I think the Lord has blessed me many times over with all my family and friends.

Sorry this is rather in haste, but comes with all my love and look forward to seeing you in September. All my love, God bless, Mum

In June a group of parents wrote to all the parents in the municipality:

We have decided to introduce a system of supervised picnics during the school lunchbreak for the schoolchildren of Satigny. They want to offer two or three times a week, under the supervision of a permanently-employed person with a small contribution from the parents. Other volunteers will be needed to take care of the children. If such a project interests you, please send us the attached answer sheet back.

The first meeting was held on September 4, and the first supervised picnic started on September 20. The existing association of pupils' parents (APE - Association des Parents d'élèves) didn't want to be involved. There were disparaging remarks made by the APE, the mayor's office and the teachers about the mothers who didn't take care of their children properly.

However, in November, the supervisor wrote: *I finish my letter to tell you that after a rather difficult start, due to the excitement of the children and the need to find a rhythm, the supervised meals have taken an agreeable turn for everyone.*

Edward was in 1st grade, for the school year of 1991-1992 and his teacher was Ms. B. In his school booklet, she wrote for the first period on October 2:
Edward is a very sensitive, dreamy pupil, easily distracted and dissipated. He lacks self-assurance and has an enormous need of my encouragement to progress a bit in his work. He cannot always concentrate on an individual or group activity. Additionally, he often feels the need to bother, tease or make faces with his fellow pupils who are embarrassed by this kind of behavior. But these last days I have felt he is listening better and is more interested by my lessons. I hope he will continue in this way.

Throughout the booklet, the behavioural themes remain the same: his lack of concentration, his relationship with the other children, his lack of self-assurance, his need of constant attention and encouragement to finish his work and the irregularity of his work performance.

It seemed that I was experiencing “sources of pressure” in a number of areas, one of them being conflict with our housekeeper. I wrote in my personal diary on October 6, at 4:30 a.m.:

There is so much going on that I need to separate things so I can think straight. Edward: There is a point that in my mind does not make sense. If John was brought up so beautifully, so stable and balanced, why does Edward trigger such anger in him? Why does he say things like, “I’ll send you away” and “If Edward is having problems it’s because you’re not being a proper mother.” Edward’s fears, in my view, are related to John, less than to me. He’s scared of John.

Being a business woman versus a mother:

<i>Business woman</i>	<i>Mother</i>
- results-oriented	- relationship-oriented
- deadline driven	- interruption-driven
- tough bitch	- lovey-dovey
- aggressive-assertive	- passive-assertive
- 8 hours a day	- 24 hours a day
- competitive, out to win/ succeed	- win/succeed

Letter from my mother on October 14, 1991:

I started this this morning and didn’t get as far as Dear Kate – I have written a little note to John. It was a super weekend, just so sorry it wasn’t longer. I’m

sorry my tum played up Saturday – it does this every now and again – so all worked out well. And Dad was able to eat before too late. I’m sorry he got cross with the children about saying “I don’t like”. It happened here and after one of his tickings-off, they stopped saying it. It really is only a habit to get your attention because they really are quite good eaters. Such is the way of children and Mums get caught in the game. Grandmums have seen it before, but don’t worry, all these things pass! May Mum make a suggestion – why don’t you leave the children behind one weekend and have a little luxury with your hubby? It’s rather nice – no matter how much you love them. There’s one thing where my man and yours differ. Yours is happy when he spends and mine is happy when he saves.

Extract from my personal diary dated November 1, 1991 at Richard’s⁴⁹:

I went to stay with Richard on a trip to England for work. He asked me to do the Lüscher test. And this is what he said:

You’d have to do a lot of negotiation around things to stay together.

The Lüscher Test:

Violet/ Green: Violet represents idealism. Green represents independent self. The mix represents the seeking to make a favorable impression of an agreeable person to the outside world, but trying to maintain the self. Creative – such as my work – sensitive, caring.

Brown/Red: Seeking out comfortable situations

Black/blue: Repression / refusal to commit to a relationship. The desire that someone else take over the relationship and basically the refusal to take responsibility.

Grey/Yellow: Optimism/ disappointment of hopes and satisfactions

Green/Yellow: Anxiety caused by the indecision.

Violet/Yellow: Looking for an ideal world to contend with the disappointment.

Distress. Lack of energy, mental energy. Likely to have a health problem soon.

Edward has come to learn about socializing. Scorpio moon, Saturn in the nodes.

⁴⁹ Richard Frost was the priest to the English-speaking Catholic Community of Geneva. He was Edward’s god-father. He moved back to England in 1987. I continued to visit him. He had taught Chinese philosophy and I-Ching at university, and he taught me how to use it.

Extract from my personal diary dated December 30, 1991:

Thoughts: I thoughtthat we would be able to start anew and change the things that are getting in our way. I started to reflect on the different difficulties that I have been experiencing which are the job with Digital, the financial problems and the relationship. It seems to me that Digital is not a healthy environment for me to be in, that ideally the package would come about, and that I can engineer that. I need to look for a new job, look at new opportunities. This seemed to be logical to me, and still does.

I looked at the relationship with John and thought about what I had said about it being like the feelings that I had when we were engaged, the difficulty I had to adapt to being part of a couple and no longer an individual. But John does not experience closeness the way I do. I like being close, trusting and intimate, but, as I tend to soak up other people's emotions and feelings in their presence, I need to withdraw, ideally in a physical sense, to regain the sense of myself and my "own-ness". It is true that I am often invaded by what others say to me, it triggers a lot to hear others talking about me and my situation. Of course, John has been very often able to override what others have said to me that may influence my opinion. He is a very capable negotiator and like all negotiators I tend to see him as a manipulator. John devours me, he gets in my way of seeing things for myself. He likes to be the dispenser of knowledge and he becomes more and more rigid in his approach to his chosen path. Although he understands my need for solitude, he does not respect it and I find it hard to request it.

There is a soft side to John which I love and which I wish I could keep. He can be loving and attentive, understanding and caring. He has showed this side a lot during the Christmas week. But it also makes me sad and depressed to be with him when he is like this because I know that this not all of him and I cannot trust the hard side of him.

Then during the night of Monday to Tuesday I awoke with the anger. I didn't sleep for about two hours dwelling on this anger I had against him. It makes me want to spit I get so angry. I felt that it would be so good to do co-counselling and that got me more angry because I know he doesn't approve of it, and he has done his best to stop me from doing any more with his putdowns, etc.

I looked at the accounts in the morning and I calculated how I could cope if I didn't have him around, and I could cope without asking for child care even! I could even pay the mortgage on my own!!!!

I do not see why he cannot get a job and bring in some money each month. When we were in the Valais and doing really badly financially I went and got a job as a receptionist at the Ecole des Roches at 2700.- a month which comes out to 16.85 an hour! I cared enough to do it. I didn't just call up my father for more money. I do not see why I should ask for more money from my father to let him continue his studies in luxury. All his colleagues, except for Brigitte, have to go to work to earn their living. Why not he? My father will not bail him out, he expects him to do something more active than faff about. John's way of looking after the finances is finding others to support him. If he leaves, he will have to support himself. That gets me so mad. If he can support himself if I ask him to leave, why can't he help support us now? Why do we have to go without things because of him? The sacrifices we have made to support him through his studies. The children have a tired, harassed mother who gets shit because she cannot be the wonderful Betty was to him. I am tired of this anger ...

All my thoughts dwell on separating. I cannot find the strength, the energy to continue in this relationship. Isn't this what I am being told? I wish I could have confirmation. I wish somebody would say with no bias, but with love, go ahead, Kate, you are doing the right thing for yourself.

1992, the year of the divorce

John and I separated in January 1992. On January 27, I wrote to Dr. A., a family therapist and psychiatrist, on the recommendation of our pediatrician, Dr. M.. I wrote that Edward was sad and needed help.

I wrote (translated from French): *"In September 1990 my husband took a temporary job in Yverdon. Edward started to tell me that his father was going to die. I took an appointment with Dr. F. at the SMP⁵⁰. She had two appointments with him, two with me and then one together with me and my husband. Her diagnosis was that Edward was cerebrally hyperactive, that he had difficulty*

⁵⁰ Service Médico-Pédagogique. This psychiatric unit is attached to the Department of Public Instruction, or Education.

knowing what to do with all the information around him, that his concentration was weak, and that he was too open to others, and that he was very intelligent. She thought that he should start a two-year course of therapy with her. She and my husband argued and he decided that Edward would not start wither her. At that time, I was very depressed. Dr. M. told me to contact you but I didn't talk to my husband about it.

Edward has told his teacher that he is happy that we have separated because there aren't any arguments and Mummy has stopped crying. He said to Dr. M. that I was not sad since my husband had left the home.

Edward and how his environment experience him:

Edward is nervous, he bites his nails, and finds it hard to keep sitting down. He listens to you if you raise your voice. He puts adults to test to see when they will start raising their voices with him. He can be very affectionate and is very loyal to his friends. He does four hours of gymnastics a week, and the musical conservatoire asked him to join the operatic choir because his voice is superb. He swims well.

On the other hand, he finds his music lessons boring. He doesn't speak either French or English correctly. His teacher, Ms. B. was 'at a loss' (her choice of words) at the beginning of the school year, but she told me the other day that he is making progress at school, and she doesn't think that he will have to repeat first grade.

He is very sensitive and has temper tantrums often. It is because of these emotional crises that many friends tell me he is strange and that he scares them. Everyone tries to calm him by force. I try to be as calm and as affectionate as possible.

Relationships with his family:

His father is very often in a bad mood. He uses very personal words, like "you are blocking our view. We can't see the television. You really are a little pest". He can never do anything sufficiently well for his father.

He has a friendly relationship with his sister who seems to be better at school and who is competitive. They have their fights. Currently the fights are about who gets to spend more time with me individually.

I love him a lot. I try to listen to him and let him express his fears and frustrations. Sometimes he tells me to be quiet. He likes to cuddle. I try not to give him too much information at a time, or to contradict him. I try to be clear and request important things. I ask him to stay seated at table, without adding that he should eat 'correctly' or something else. (I realize that I keep on using the word 'try' and I do succeed about 85% of the time.)

How I see him:

I see him as someone who is very frightened, who has doubts about himself. He is scared of failing so he doesn't start anything easily. He tells morbid stories of babies that were crushed, or that he was drowned in the lake. I fear for him because he doesn't seem to have either the courage or the ability to 'get out of this situation'. And I fear that I won't be able to help him alone.

My request:

Seeing that we are both quite fragile, I would like to meet you with Edward so that you can help me with good advice. I suppose it is natural that I would like to meet you as soon as possible, but understand that you are very busy.

Beatrix joined us for the first session with Dr. A. During the session, which took place in a room more like a living room than a meeting room, Edward lay on the chaise-longue and ignored us, and Beatrix lay on the carpet crying. At the end, he said that he would like me to come back for some sessions on my own to 'learn about leadership' because I had my hands full with Mr. President and Ms. Princess. Subsequently, our sessions focused on coping with the children, and he told me that it might be a good idea for me to start doing psychotherapy for myself. He had many a good idea. Edward had the tendency to open the fridge door and serve himself while I was cooking supper. Dr. A. told me to tell him in a directive manner something similar to, "you may eat a yogurt while I am cooking supper", and not let him choose what he wanted.

As Beatrix was telling me during that time that she was going to marry her father now that we were separating, he practiced with me until I could say, "it is really wonderful that you love your Daddy so much that you want to marry him when you grow up. What a wonderful proof of love to want such a thing." A few days later, John was over visiting when she made her claim, and I answered with what I had practiced. John was very surprised. Beatrix grinned and never mentioned marrying her father again.

In May, I was contacted the SPJ (Service de protection de la jeunesse⁵¹), who were required by the court to assess my situation and that of the children. Our divorce was pronounced on June 18. According to the legal agreement, I was granted the parental authority and the custody of the children. John was granted “*a large right of visit, which unless otherwise agreed to by both parties, will be exercised every other weekend and half of the school vacation*. He was obliged “*to pay child per month and at the beginning of each month, a contribution towards the maintenance of each child*” different sums according to the age of the child. I paid all the lawyer’s fees. Later in the year, I was asked by the court of guardianship to submit an inventory of the children’s goods. I wrote up a list of all the belongings that John took with him

Edward started individual speech therapy classes twice a week with Mrs. Zwahlen in April. This pedagogical and therapeutical measure was offered by the Service Médico-Pédagogique, and paid for by the federal Assurance Invalidité (AI or Disability Insurance), part of the social security services. Mrs. Zwahlen told me that Edward always said, before trying to do an exercise, that he wouldn’t be able to do it. She said that he was making progress but it was his lack of self-assurance that was his main obstacle.

At the end of the school year in June, Edward’s teacher wrote: *I find that Edward, in spite of everything, has made great efforts. He has become more open, receptive and perseverant towards his work*. Edward graduated from first grade. In Geneva at this time, children did not automatically pass their grade. On the last Saturday of the school year, there was a primary school graduation ceremony called “les promotions”.

Extract from round-robin letter from the association of supervised meals of Satigny, dated August 17, 1992, translated from French:

Your children will be taken care of, according to your request, on a permanent basis on every Monday, Tuesday, Thursday and Friday. He will receive a hot meal, and will be supervised from 11:45 until 13:30.

Please reserve the date of our general assembly meeting on September 22, 1992 at 20:30.

⁵¹ The Youth Protection Services

Dear Volunteers,

Please find, here below, the roster for the first two weeks.

Monday 31 August 1992: Aupair girl (Cathryn)

In order to simplify things, the committee has decided that all children will pay the price of 7.50 and that the association will pay for the volunteers' meals.

Family calendar entries for August, 1992:

August 3: Back from holiday in UK

August 10 and 11: B&E at John's

August 12: Fifi's birthday

August 15 and 16: B&E at John's

August 24: School starts

August 31: Kate in UK

For the beginning of the school year, Edward was enrolled in extra-curricular gym class. I decided against enrolling him in Catechism. He had Ms. B. again as his teacher for 2nd grade.

At the end of the first grading period, on September 29, she wrote:

Edward is a sensitive pupil. He appreciates to dialogue with the adult and his relationships with the other children are improving progressively. Currently he is having difficulty in adapting to the rhythm of this second grade. He is quickly overwhelmed by the instructions given in class. But this is due to a large extent to his lack of attention and concentration. He really should try to work without the teacher being constantly by his side.

Family calendar entries for September, 1992:

September 2: Kate back

September 11: School outing

September 12: (Saturday) School

September 15: Beatrix ate at Cléa's

September 18: Kids ate at home

September 19: B with Kate, E at gym with John

September 20: B with Kate at Fer à Cheval, E with John

September 22: B goes to eat at Patricia's

September 23: Ines' party

September 24: E goes to eat at Marc's

September 25: Kids eat at home

September 26: School. John picks up kids from school. Clea's party

September 27: John spent afternoon with us

September 28: Kate away in Vevey

On October 1, I wrote to my parents:

I was asked by John to give it another try now that he has got a job as the director of the bachelor's program for the hotel school in Bluche. He wants to take care of me. The offer was tempting because the past few weeks I had been more scared of being alone, but it isn't realistic. After all, who wants to live in Crans-Montana?

Cathryn, our aupair girl, left us on October 10. On October 13, Edward had an accident on his bike after school. He rode down a path and right on to the road and was hit by a car. He broke his leg. I was at work and had come back from a meeting. My colleague, Nanda, had taken a telephone message for me. I went to the hospital and found that Edward had his leg plastered. I no longer had a live-in au pair girl and I was teaching a two-day course the following days. I couldn't leave Edward alone at home during the day. Talking to Dr. Braun, the doctor in charge, he proposed to keep him in hospital for two nights to help me out, which it certainly did. I took him back for a check-up on October 27. His leg seemed to have shrunk and the leg plaster was loose. The doctor's manner was brusque and he said that Edward had to go back in the following day for a new plaster. I accompanied him and the nurses put him on an examination bed. Edward asked me to pass his backpack and drew out a toy gun which he slipped under the pillow. He told the nurses, much to their amusement, that he was going to shoot the doctor if he wasn't nice to him. The nurses told the doctor when he came in. He looked surprised.

Family calendar entries for October, 1992:

October 2: Kids eat at home

October 3: J. picks up E&B at 11:00

October 4: E&B back

October 5: Esther starts

October 7: 8:00 Speech therapy, Gym, John for supper

October 9: Lunch at home

October 10: Cathryn leaves

October 13: Lunch at home, Edward's accident

October 16: Edward out of hospital

October 20: Parent evening
October 26-30: School vacation
October 26: Gruyère with Bev and David
October 27: home, 16:30 Dr Braun
October 28: Edward – hospital
October 31: Halloween, Bea at Laura's overnight

Family calendar entries for November, 1992:

November 3: Dr. Braun 17:30
November 6: Kids to John at 19:30
November 7: School
November 8: Kids return
November 9: Kate in UK
November 10: Dr. Braun 17:30
November 11: Kate return at 23:00
November 16: Dentist 8:10
November 17: Meal duty
November 18: Speech therapy, Dr. Braun
November 21: School
November 22: John moves
November 25: Dentist 8:10
November 27: Kids lunch at home
November 28: 10:00 Dr. A.
November 30: Kate at Hotel Beaurivage, Nyon – to December 1

Edward's school subjects, French, mathematics and writing, were graded at one of two levels: sufficient or insufficient. By the end of the second period, on December 8, the teacher graded him 'insufficient' in mathematics.

Family calendar entries for December, 1992:

December 4: Granddad arrives
December 5: Oskar's party 3-6
December 12: DEC party for kids at 14:00, Supper at Yves
December 16: Edward's party 3-6, Philippe & Pat
December 17: Edward's birthday, Christmas party
December 18: Kids to John at 19:00
December 19: School
December 20: E&B return at 19:00
December 23: Vacation

December 24: Mass at 18:00
December 25: B&E to John's 12:00-18:00
December 26: B&E to John's 11:00-18:00
December 27: At Mary and David's
December 28: Kids at home
December 29-30: At Monique's in Crans
December 31: At Eva's

Letter to John dated December 7, 1992:

This is to confirm that the children will spend the following days with you in December and Christmas Vacation:

Friday, December 18, 19:00 – Sunday, December 20, 19:00

Friday, December 25, 16:00 – Saturday, December 26, 19:00

Saturday, January 2, 14:00 – Saturday, January 9, 19:00

Edward will be celebrating his birthday party on Wednesday, December 16, in the afternoon with his friends. Should you wish to take him after school on December 17 for the evening, please let me know.

1993, the year Edward went to special educational needs class

For the one week vacation in February, we went to the ski resort La Clusaz with my parents and Cathryn. I enrolled the children in ski class each morning, and went off skiing on my own. John came up to visit us one afternoon and skied with us all on the beginner's slope. When he left, I felt sorry that he was going, that he didn't belong to the group of us in the same way.

A photocopy of pages 100-108 from the book *La méthode Coué, la maîtrise de soi-même par l'autosuggestion consciente* (The Coué method, mastering oneself through conscious auto-suggestion). There is the name of Monique C. written in pencil, and underneath written by Edward's teacher, Ms. B, is "From the teaching assistant for Edward's mother". The Coué method is often ridiculed as being very simplistic. It is based on repeating the affirmation, "Every day, in every way, I am getting better and better."

The text concerns the parenting of children. Coué (born in 1857) states that parents should choose well the people to look after their children, that these people should have the qualities that one wishes one's child to have, and that everyone should inculcate the notion that work is indispensable to man, and that the person who does not work is a useless person (page 100). He then talks

about how to develop self confidence in children. The following lines were underlined by the teaching assistant:

« Leur apprendre surtout que chacun doit partir dans la vie avec l'idée bien précise, bien arrêtée, qu'il arrivera et que, sous l'influence de cette idée, il arrivera fatalement, non pas qu'il doive tranquillement attendre les événements, mais parce que, poussé par cette idée, il fera ce qu'il faut pour cela ; il saura profiter des occasions ou même de l'unique occasion qui passera près de lui, cette occasion n'eût-elle qu'un seul cheveu ; tandis que celui qui doute de lui-même c'est le Constant Guignard, à qui rien ne réussit, parce qu'il fait tout ce qu'il faut pour ne pas réussir. » (Coué, 1990, pp. 101-102)

In the following pages, Coué gives advice on the type of affirmations that can be proposed to children by their parents and their teachers. In particular for teachers, and underlined by the teaching assistant, he states that teachers should tell their pupils:

“De plus, vous aimerez le travail, quel qu'il soit, mais comme actuellement il consiste pour vous dans l'étude, vous aimerez toutes les choses que vous devez étudier, même et surtout celles que vous n'aimiez pas autrefois. Donc lorsque vous serez en class, et que le professeur fera une leçon, vous porterez uniquement, exclusivement votre attention sur ce qu'il dira, sans vous occuper des sottises que pourraient faire ou dire vos camarades et surtout sans en faire ou en dire vous-mêmes.

De même, lorsque vous travaillerez seuls, à l'étude ou à la maison, que vous ferez un devoir ou que vous étudierez une leçon, là encore vous porterez uniquement, exclusivement votre attention sur le travail que vous faites, et vous aurez ainsi toujours de bonnes notes pour vos devoirs et vos leçons. »

Coué, 1990, pp. 107-108

At the end of the following period, March 9, 1993, Edward was graded as 'insuffisant' in mathematics and French. His teacher wrote:

Edward's level of reading does not reach the level required for the second primary class. Technically he has progressed, but Edward hesitates over many words. He isn't always capable of finding his way in a text, or following the class when we do group lessons. He still has difficulty in reading and

understanding the instructions given in class, which hinders him from doing his written exercises on his own.

He does not do his homework regularly. The notions that we have studied of grammar, spelling and conjugation must be exercised more.

In mathematics, the acquisitions are not being done correctly. The relations, the coding in different bases, the classifications, addition and subtraction must be seriously consolidated.

At some point, I had an angry exchange with Ms. B., who told me about the necessity of doing Edward's homework with him. I told her that I thought that children his age shouldn't have to do homework, and if they did they should have sufficient instructions to be able to do it on his own. She was very indignant and told me that it was a mother's job to do homework with her children. I told her that I had a job working in a company, and said that had I known that I was supposed to teach my children I would have become a teacher myself. That way I would have known the mathematics being taught and I would have the same schedule as my children.

I received a letter from the school inspector on asking me to meet with him and Ms. B. on April 1st to discuss Edward's future. I wrote to Dr. A. asking him if he could come to the school because Ms. B. wanted to talk to him about Edward with the assistant teacher. We had this meeting on April 27 at 12:00 over the lunch break. I remember seeing him at the school and walking up to the classroom together with him, and thinking how wonderful it was that he had crossed the city to attend this meeting. During this meeting, we agreed that Edward would go to 'specialized class' (Special Educational Needs) for his third grade. I didn't know the Swiss school system and I didn't understand all that it meant for Edward to go to this class, that he would not be able to re-access normal class. I thought that he would be receiving extra assistance to get him up to the level required and return to normal class. The other option was for him to repeat second grade. In my class on general pedagogy at university, a professor talked about his research in the Geneva school system, and said that having children repeat a year did not improve their performance. He said they had to deal with teasing from other children about being held back and they got bored with doing the same subjects and exercises. At that time, 10% of all school children were repeating in primary schools in Geneva. He talked of the

pressure that the system put on the teachers obliging them to hold back 2 pupils out of their class.

On May 12, I received a letter from the inspector of the special educational needs class confirming that Edward would start in Ms. P.'s class on August 30. A school bus would pick him up in the morning and bring him home at the end of the school day, and he would eat at the school canteen. I was told to contact the AI (Disability insurance) to get the required funding. The disability insurance made their "decision for readaptation measures" on December 21, 1993. They agreed to continue funding Edward's speech therapy with Mrs. Zwahlen until the end of December, and to contribute, as of August 30, 35.- francs per day to Edward's special schooling, and 7.- francs towards his lunches, and to pay for the school bus.

I wrote to my father on April 16, 1993:

I was wondering only the other day when you would be egging me on to find another man. Seeing that I am enjoying life as a single working parent it is going to take one Good Enough Bloke to get me to change the life I've established for myself and my kids. I am not averse to taking on another bloke because I would like a special person in my life, and I would like to be someone's special person. However the advantages of celibate life outweigh the disadvantages and the blokes I have met in the past year haven't managed to tip the balance in their favour.

When I was about 15/16 and you were fed up with my trials and tribulations with Tommy, you told me to go out with an Englishman to which I remember replying, "Find me one decent one". ... As the years have flown by, the word 'decent' has been expanded to help us both establish what it means I have put together the following job description for your (and Mum's) eyes only. If you think anyone matches up then you are allowed to introduce me to him on my next visit.

The Good Enough Bloke should ideally

Physically – be not shorter than 165 cm, not heavier than 95 kilos, and not younger than 35 and not older than 50.

Nationality – be preferably Western European and seeing that stretches as far as California including North Americans.

Professionally – should have succeeded professionally and enjoy his job and his choice of profession. Preferably be a university graduate, or some other equivalent. Not be taken up totally by achievement in his job, not be dependent on others' recognition of his achievements, be earning a decent salary and not work more than 10 hours a day, 6 days a week.

Spare time – if he sails, must be happy sailing alone (that goes for any spare time activity), if he can't mend things around the house should feel happy about paying for it to be done and organizing its being done. Should have at least two spare time activities he enjoys.

Romantically – send me flowers at least once a week, plan and organize surprise outings (not to the boat show or the telecom exhibition), take me shopping at Yves St. Laurent at least once a year.

Responsibility – manage his own bank account and accounting, do his share in the house, or alternatively pay for it, deal with his parents, ex-wife and children by himself, and take my kids on.

Spiritual development and other personal values – if of any psychological inclination, must be Jungian, Adlerian, Rogerian, but not Freudian. Have any religious denomination, except fanatical. Practice some form of relaxation, meditation or reflection. If not concerned too much by all the above, must be happy to let me pursue my own spiritual and self development which means weekends away and not bug me about it.

Not be racist or sexist, be respectful of others, be able to see different points of view, and be able to express anger and other feelings.

Practically – agree to separate bedrooms, agree to working women, agree to the equal rights amendment – and not bitch about it.

Shut up while I'm reading.

Sexually – capable.

I think that does it. If you send this to my brothers, my sister, my aunts or uncles, or Prince Charles I will personally wring your neck. Your beloved daughter, Kate

During this time at work there was also a lot of pressure. Many people in the training departments had been made redundant. On April 8, I started seeing Evy, a Jungian depth psychologist. I interviewed for the position of Management Development Manager for the airline Swissair, and started negotiating with my boss around the possibility of being made redundant as well. When I first presented my case saying it would be advantageous for all concerned if I were the 'next on the list' to go, he said that I wasn't his first

choice but that he would be much happier to fire someone who wanted to be fired. We agreed that I would receive my redundancy letter on June 30. By July 1, I had not received the letter. There were other managers in the company who did not want me to be made redundant. The HR manager said that nothing was decided. Eventually I received the letter at the end of the day. The following day I booked flights for Edward, Beatrix and I to go to Scotland for two weeks, followed by two weeks in England. We spent two weeks in hostels at Drumnadrochit in Inverness and on the Isle of Skye. During this time, the HR manager from Swissair called me asking me to take the position with Swissair, but I declined. I wanted to go freelance.

When we came back from our summer vacation on Friday, July 30, John picked us up from the airport. He told me that he would help me out with the children on Saturday. I had to prepare their clothes and buy different things for them to take to summer camp 'Groenroux' on the following day, July 31.

On the family calendar it says, "*the day I found Jean-Luc in my kitchen*". Jean-Luc was John's friend. They had met through work as Jean-Luc was supplying the school with laptop PCs. The story goes that I was cheesed off that John had gone off to Jean-Luc's office to pick up his new laptop and had not come to the house to look after the children. I went off to do the shopping with the children, and got back to find Jean-Luc's sports car parked in my drive way. I had many shopping bags that I brought in. John introduced me to Jean-Luc and said that they had talked about my forthcoming needs for setting myself up as a freelance trainer, and that Jean-Luc would supply me with a fax machine and a printer for free. I remember going upstairs to my bathroom and thinking furiously about this paternalistic behavior, but also it seemed like a good deal. Jean-Luc remembers a "fury coming into the kitchen wearing leggings and Birkenstocks". We agreed that he would come and deliver the machines on the following Friday, which is also on my calendar, and on the same day at 17:00 the kids returned from camp. Jean-Luc's story is that he came around and installed the machines and we started talking, but I didn't offer him a drink. When I finally did, Edward started making a fuss, and he decided to leave. My story says, "I didn't expect to like talking to this man, I didn't expect him to want to stay and talk to me. I thought he would install the machines and go."

I noted in my work diary that I saw Jean-Luc on September 2. He asked me if I could help prepare a presentation and came over to the house. I was looking for

business, had started an outplacement program and was spending a lot of time with the children. My work diary was full of appointments for the children. I would take them to school for 7:55 and then rush home, do housework for half an hour, and then start working at my kitchen table. Jean-Luc asked me also to do a job profile on the role of salesperson for his company, and I worked on that during the month of November. We started dating at the end of the month.

In January 1994, we went on vacation together in Martinique while Jenny came to look after the children. As we were driving home from the airport, we met up with John leaving the house. He introduced us to Judith, his girlfriend.

The youth health service sent me various papers in the first term of school to inform me of Edward's various appointments for a dental check-up and a physical check-up. His teeth were in good shape. His posture showed a 'normal attitude' and he weighed 31.6 kilos and was 140.5 cm tall.

Edward started his third grade in the special educational needs class on August 30, 1993. His first period of evaluation was from September 9 to November 23. The grading levels were different; there were three levels: very satisfactory, satisfactory and a little satisfactory. He was graded satisfactory for his evolution in his personal work, his relationships with other pupils and the rules of communal life. His teacher, Mrs. P., wrote: "*Attention! However do not panic when I give you instructions and you have to read them. Try not to forget your homework. Bravo for the better attention that you give to the others!*" His learning progress in French, mathematics, artistic activities, writing were graded satisfactory, and physical education and environment classes were very satisfactory. Parents were required to sign this booklet, on each page of evaluation. John and I both signed.

John and I were communicating by fax to organize the various events, like school shows and weekend visits. I wrote on December 7, 1993:

Next weekend:

1. *Saturday – see attached information about the Escalade celebration. I didn't send the coupon for the soup. Ms. P. says you can buy tickets for the soup on the spot.*

2. *Sunday – I'm taking Beatrix to the parade at 16:00 in town and will be back at 19:30? Would you like to a) keep Edward overnight and take him to school on Monday morning? Or b) bring him back at 20:00?*

Following weekend:

1. *Edward's party is on Wednesday, 15th.*
2. *Would you like to have Edward and Beatrix on the 18th? They haven't got school that day. If you like they can stay the night.*

Tuesday, December 21 Christmas shows

They both have their respective shows the same evening so I told them that you would go to one and I'd go to the other. I don't have full details yet. I propose that I go to Edward's seeing that you went to his class presentation and I went to Beatrix's.

Fax message from John on December 7, 1993:

For next week-end:

I will pick Edward up from school on Saturday at 11:00 and return him to Peney on Sunday around 18:00.

For the following week-end:

The party for Edward on the 18th is now obviously modified. I will give his birthday present to him this weekend, in that way you can make new plans without having to take me into account.

For the Holidays:

I will take Edward and Beatrix, as planned, from the 24th until Sunday 9th.

Please advise when (time) and where I will meet them and return them. If I have got something wrong please advise soonest, thank you.

Fax message from John on December 10, 1993:

I will be at school tomorrow morning around 10:00. For Sunday I will probably also go to the cortège (the Escalade's parade) and will bring Edward back after. For December 21, I will go to Beatrix's, please send time and place.

For the weekend of the 18th I will probably be busy preparing for the holiday week so it might be better they stay with you (also I thought that Gran and Granddad are there with you at that time).

For the holidays we will be needing warm clothes and party dress. We are not going to the mountains however we are most probably going to the Disney hotel after New Year.

For January and February I do not have all travel plans set yet. We will therefore decide on dates now and I will accommodate afterwards. I suggest the following weekends with me: January 21/22, February 12/13 and 26/27. Please confirm if the above is suitable.

I held a birthday party for Edward at the ‘carnotzet’ at the municipal hall of Satigny on December 15. We invited his old school friends from Satigny to dress up in their Escalade costumes. Edward was dressed as Robin Hood.

1994, the year Edward went to private school

Edward’s second evaluation came on March 15, 1994. He was graded ‘little satisfactory’ in his relationships with the other pupils. His teacher wrote: *Edward has too often difficulties with his friends. And it is always the others’ fault!* His grades for his work remained the same, except for artistic activities and writing that increased to ‘very satisfactory’.

Edward started psychotherapy with Mr. J. on March 8, 1994. The AI (Assurance invalidité) decided to fund the psychotherapy up until June 1995. At the same time, he stopped his speech therapy sessions.

The child psychiatrist, Dr. P.-C. of the SMP wrote a report on March 22, 1994, translated from French:

Edward was seen at our service for the first time in 1980 for temper tantrums linked to frustration, for oppositions, and auto and hetero aggressiveness. Edward is seen as a hyperactive child, excited, who talks very rapidly with abundant language.

He gives himself an image of being alternatively grandiose or devalued accompanied by affective expressions of sadness, and expresses real suffering. He protects himself from this by his imagination. At this point in time, a specific aid was not envisaged for Edward but interviews with his mother who was facing a conflictual conjugal situation, which led to divorce eventually.

A second consultation took place in May 1993 in view of his integration in the special needs sector seeing his important learning difficulties. Edward had little structure in his way of approaching various school tasks, his work rhythm was slow, and he was lacking concentration and attention. Because of his lack of

self-assurance, he had to be supported and stimulated in his tasks, otherwise he would go from one task to another.

Elsewhere, Edward followed speech therapy and family therapy.

In March 1994, I saw Edward myself at the request of Mrs. Lindley to evaluate the indication of psychotherapy.

Edward presents himself as a boy who is tall for his age, with an ease in relating to others. He becomes quickly familiar with the attitude of a gentleman. He expresses right away his intense feelings of depreciation. He seems to be overwhelmed by sexual fantasies that he has difficulty in mastering.

He told me of the many accidents that he has had, the numerous times he has been to hospital and his anguish linked to these events.

Edward is very conscious of his difficulties in relating to other children, and suffers from it. He is eager to establish a relation with someone who can help him.

It seemed to me that psychotherapy was necessary for Edward and he started shortly thereafter seeing Dr. L. privately.

He took the bus from Meyrin, changing buses in the center of the city, to Champel for his sessions. Mr. J. worked for Dr. L., one of the few child psychiatrists who said he could take Edward on during the school year. I picked him up from Champel after his session. One day, after getting off the bus, he decided to see if he could hold on to the back of his bus and be pulled on his skateboard. He fell over in the road, hitting his head. He was just outside the nursing school, and someone helped him to get up and took him over to Mr. J.'s office.

Edward's third evaluation came on June 20, 1994. He was graded in between 'little satisfactory' and 'satisfactory' in his relationships with other pupils. His teacher wrote: *Edward is organizing himself better in his work generally, but he still has too many exercises that have been started and not finished. He has made enormous progress in listening to the others and letting them talk.*

In his school work, he was graded as having made sufficient progress in all of the subjects. The teacher wrote: *I am very satisfied with all the positive changes that Edward was able to make this year. I hope that he keeps his self-confidence, that he doesn't forget that he has rich possibilities within himself.*

He had passed third grade, he had graduated to fourth grade in special education needs class. This is not what I had expected. I expected him to be reintegrated in to the main stream class.

Edward started fourth grade at another school, Les Boudines, in the same town of Meyrin. He was picked up by the school bus, and had lunch at the school canteen. His first evaluation period was from August 29 to October 3.

Your child:	Rarely	Sometimes	Often	Very often
1. Respects the rules of the class and the school.		X		
2. Is tolerant towards his colleagues.		X		
3. Knows how to listen to others.		X		
4. Participates actively in lessons.			X	
5. Concentrates when doing individual activities.		X		
6. Applies the instructions given either orally or in writing.			X	
7. Organizes his work.		X		
8. Finishes his work on time.		X		
9. Knows how to learn from his mistakes to improve his work.			X	
10. Presents carefully done work.		X		
11. Takes care of school material.			X	
12. Does his homework carefully.		X		

His teacher, Ms. S., wrote: *Edward is very chatty and often disturbs the group. He does not always show a lot of enthusiasm to do the work requested. And yet,*

he possesses interesting knowledge that he likes to share during the oral lessons.

About this time, the woman, Mrs. O., who supervised the group of children from the special education class called me up. She told me that she was worried about Edward. He often walked alongside a steep drop and hung by his hands over the drop. She said that she had talked to his teacher about it, but that she hadn't seemed to take any action. She wanted me to know. I remember talking to Edward about it and telling him that we would look in to it.

On October 24, 1994, we received a letter from the Leman College, a private school, accepting Edward as a pupil in Grade 4 of the English-speaking section.

On November 1, 1994, I wrote to the school inspector of special education in the Geneva public schools:

As agreed with your secretary just before the school vacation, I am writing to you to confirm my decision to send my son, Edward, to Leman College.

The reasons for my decision, as already discussed with you, the following: Edward feels that he has been put into third grade again in Mrs. S.'s class, and that is another failure because he expected to be in fourth grade in a normal class.

His behavior is not improving according to Mrs. S.'s remarks. Mrs. O., the supervisor at the school canteen, says that she is worried about his behavior. She says that he is also bullied in a nasty way by the other children in the 'normal' classes.

The competition with his sister is very strong, and he seems himself losing. It has, therefore, been decided with his father, the psychiatrist Dr. L. and myself that we need to remove him from this situation.

His teacher, Mrs. St., did a first progress report in December. She wrote:

It is difficult to assess Edward's academic abilities at this point, due to his short period of time in Grade Four. However, he is currently working at Grade 1 level in English Language and Reading, Grade 2 level in Mathematics and Spelling. At all levels, Edward requires constant supervision and guidance, as he finds it very difficult to work independently. He has great difficulties with English spelling, even at Grade 2 level, and scores poorly on his spelling tests. He must work much harder if he is to progress – his concentration powers are poor. Edward's social behavior also is a cause of concern, and needs urgent

attention. He is too frequently involved in playground incidents which involve the use of aggressive physical behavior, or undesirable language. His behavior within the classroom is quiet, but he is often annoying other children, or being silly. He must make a much greater effort to conform.

His English as a Second Language teacher wrote that he had made a good start. In Physical Education, his attendance and results were excellent; his effort above average, his sportsmanship satisfactory, and his behavior needed improvement. In Art, his skills and creativity were very good, and his effort excellent. The music teacher wrote: *Edward derives a lot of pleasure from the music classes, and has a genuine interest in the subject that I hope can be expanded upon. He participates well, and it will be interesting to see what he produces in the more academic topics to come.*

1995, the year Edward was diagnosed with ADHD

By mid-January, 1995, there were weekly reports sent to me about his behavior. He was involved in various incidents during outdoor recess. He had silly behavior in the dining room. Other children complained about his distracting and annoying behavior in class. The pattern persisted and on March 3, the teacher wrote: *Edward has been quieter this week. There have been less incidents than usual. His rapport with his classmates is not improving, and his isolation is becoming more pronounced. He struggles to complete any assignment.*

We moved from the house in Satigny at the end of December, 1994, to an apartment in the centre of Geneva, on the right bank. The apartment on the third floor was much larger than the house. Jean-Luc had moved into an apartment on the fifth floor in April 1994, and we thought that this arrangement would be best. John and his girlfriend, Judith, moved into the house in Satigny.

On January 25, 1995, I wrote to John with the schedule of school holidays. I wrote: *I realized that you don't have the dates so I've put them down here. As we had agreed at the beginning of the school year, I took care of their vacation in October and will take care of February. You took them for Christmas and will take care of the Easter vacation. We have an additional load as Edward has longer vacations at the college and at different dates from Beatrix. For the summer vacation and next school year, we can discuss this whenever you like. If you want we can reverse what we have been doing up until now.*

Edward's teacher wrote a more official report on March 24, 1995:

Edward is finding it impossible to work at the level or pace of Grade Four. His reading shows slight improvement, but he is unable to concentrate for more than a short period of time, so his progress is slow. He is currently reading at Grade Two Focus level, which is specially directed towards children who do not have English as their mother tongue. His spelling is very poor, and he has made very little progress in the retention of spelling patterns. He now manages to put some sentences together, but in general, his writing is that of a child of Grade One Level.

In math, Edward is working steadily through the Grade Two programme, though he needs constant encouragement to stay "on task". He has completed addition and subtraction of two digit numbers, and some simple geometry, but is careless about signs such as plus and minus. His calculations are quite accurate. With more individual attention and tuition, he should be able to progress more rapidly.

Edward finds both the Science and Social Studies programme very difficult, and though he listens in, his attention often strays, and he is unable to complete any of the follow-up work.

Socially, Edward finds it difficult to mix successfully with his classmates. His immature and sometimes explosive nature causes him to be rejected by the other children, which in turn leads to more negative behavior. This is a circle which is difficult to break. Edward seeks the company of much younger children during recess time, though of his "play" results in conflict or aggressive behavior of varying degrees.

The school psychologist, Mrs. L., attended a meeting with John, myself and the head teacher around this time. I remember feeling attacked by her. She inferred that I was not aware of what was going on, and that I didn't care. At one point I started crying and responded that I did know what was going on, but that I didn't know what to do about it. After that, she became more helpful and proposed that I go to see a school in the center of Geneva where they had small classes, the Farny School.

She wrote a report about Edward on April 5, 1995, (translated from French):
Edward has just spent some months in the English class of 4th grade at the Leman College. Coming from the Geneva school system, where he was in special education class, he has difficulty in adapting to a normal school rhythm.

He does not have the necessary “tools” to follow a class with many pupils. He does not follow instructions given to the whole class and doesn’t know how to work autonomously. He certainly needs much individual attention to catch up with his academic delay, and also special school and psychological support to gain confidence in himself and his possibilities.

He is currently not at ease because he is aware of his deficiencies. The Farny School where he will be attending in his habitual language of French and where he will be in a small class will certainly offer him a frame, better adapted to his problems.

I hope that he will make friends of his own age because he needs to be socially at ease.

I hope that this change during the school year will be beneficial to him, because until now Edward has not found a school that suits him or where he is happy.

The brochure of the New Farny School states and translated from French: *Miss Alice Farny founded the school in 1925. The employees of the school and a group of parents decided to continue the school after her departure, and so in 1981 they started the New Farny School (La nouvelle école Farny). In 1991, the school was associated with the Benedict School of Geneva that ensures the management and the secretariat. A pedagogical supervisor manages the school activities and the extra-curricular activities. At a time when most schools tend to grow and increase their numbers, it is useful to keep a small school with a human dimension that can respond to a particular demand.*

Situated on the right bank, behind the Voltaire college, in a house surrounded by a garden, the Farny school welcomes between ten and fifteen pupils per year and offers personalized, traditional tuition.

Edward started at the Farny School on April 24. His teacher was Mrs. Iovino, a French woman approaching the age of retirement. She wrote two sentences in his school report at the end of the school year: *Edward should leave his habitual lethargy towards school work and become responsible next year. School work to be done during the holidays.*

The director of the school wrote to me on June 7, 1995, inviting me to enroll Edward and to contact either him or Mrs. Iovino to discuss any points or ask

any questions about both the primary and secondary classes. He wrote: *I hope your child finishes his year with pleasure.*

On July 10, I wrote a letter to John, which I apparently never sent. I said in the letter that I was sending him the bills for the different summer camps that the children would be attending during the month of August when he was supposed to have them with him.

I wrote: You recently told me that it can't be much fun for the children to have to leave their home every other weekend and go away to Dad's. Seeing how happy your children were after two weeks of holiday with you is the proof that your children adore you and want to spend time with you. What I think must be really hurtful is the scene we had one Saturday morning where you and Judith explained to me in front of the children how you could only have them for two weeks in the summer because you were so terribly busy. You have the legal responsibility of having your children under your care for half the school holidays. The chart I made up, around your availability, back in May is quite clear when you have them. I spent a day finding summer camps for you. Child care is roughly 10.- francs an hour. You can buy a book at Naville called Parents Genève that tells you where to find child care. You can let me know on July 31 where they are going. If you don't organize appropriate child care for them, I will have them. But you will not have them for the rest of the year for weekends or holidays. I am quite clear: either you look after them properly during the month of August or you will not have access to them until January 1st, 1996.

The children attended a day camp from July 31 to August 4 at the Maison La Greve in Versoix, about 10 kilometers from Geneva. The theme was making and playing with masks. The first day I came to pick them up, Edward was climbing up in the large tree in front of the old house with another boy. Perhaps they weren't supposed to be up there, but it seemed like he had made a friend. His name was Thery. In the family calendar, it says that Edward spent the Tuesday night at Thery's house and Thery came over to sleep on Thursday night. Thery's mother gave me two pages of dietary requirements for Thery. On the second page, it states: "It only takes one sweet, cake, biscuit, soft drink, etc. to provoke a reaction in Thery that will last between 2 and 4 days." His parents explained to me that Thery was hyperactive and lent me a book on the subject. I called Dr. M., the pediatrician, and asked her whether Edward could possibly

have ADHD (Attention Deficiency and Hyperactivity Disorder). She said to me that she could envisage the possibility seeing that Edward seemed to be having difficulties in spite of me providing a more stable home environment for the past two years. On August 7, she sent me two evaluation forms, one for attention and the other for hyperactivity, that she asked me and Edward's teacher to fill out. It may be that the teacher, Mrs. Iovino, did not fill out the form until the start of the school year.

The teacher's evaluation of his attention profile

	Never	Sometimes	Often
1. Finishes work that has been started.			X
2. Cannot concentrate, cannot be attentive for a longer period of time.		X	
3. Cannot sit still, hyperactive.	X		
4. Is continuously wriggling about.	X		
5. Day-dreams or is inattentive.		X	
6. Is impulsive, acts without thinking.	X		
7. Has difficulty following instructions.		X	
8. Talks without waiting his turn.	X		
9. Does sloppy work.	X		
10. Is inattentive, easily distracted.		X	
11. Talks too much.		X	
12. Never succeeds in doing the tasks requested.		X	

Dr. M. gave me the name of an English-speaking educational psychologist, Mrs. T.. I met with her on August 15, and took Edward on August 18 for the first session of testing. She worked from her home about 12 kilometers outside Geneva, far from public transportation. He had two sessions of testing with her and she wrote up a report in English on September 22, 1995.

She wrote in the summary:

Edward emerges as a boy of low average general ability with low average verbal comprehension and average non-verbal – more practical skill – ability. Presently, all of his achievement ages are below would be estimated for a child of his age and general ability. It appears that Edward has primary attention

deficit hyperactivity disorder (ADHD) and specific learning difficulties (dyslexia).

Presently Edward is sad and shows symptoms of anxiety, particularly relating to school. At school his “coping style” to deal with difficulties seems to be acting the clown, in addition, to a certain level of defiance.

Any analysis of Edward’s strengths and weaknesses is based on personal history, on school comments and results since he was very young, on interviews with the parents, and on the tests given.

Strengths:

- *Abstract reasoning ability – particularly visual*
- *Visual recognition*
- *Perceptual organization*
- *Ability to relate to adults and younger children*
- *Realistic view of his weaknesses*

Weaknesses: (given in detail with remediation advice)

1. *Selective attention dysfunction (attention deficit)*
2. *Memory dysfunction (attention-retention)*
3. *Language – receptive and expressive in French & English (similar level in both languages)*
4. *Sequential dysfunction*
5. *Fine-motor dysfunction*
6. *Low self-esteem, feeling of sadness (subtype cognitive and attentional)*

Concluding remarks and further recommendations

At present I would recommend the following:

1. *Regarding language therapy that Edward be followed by Ms. B. She has offices in Nyon, Gland and Rolle. Her costs are covered by the Swiss Assurance Invalidité.*
2. *In addition to language therapy, I suggest that a stimulant medication be appropriate to try at this time as part of a total management programme.*
3. *Edward’s progress should be carefully monitored regularly. Research has shown that a team approach meets with the most success with children presenting attention deficit disorder. Frequent communication between parents, doctor, teacher(s), and psychologist is important therefore.*

4. *That Mr. and Mrs. Lindley read as much as possible about attention deficit hyperactivity disorder and specific learning difficulties to enable them to better understand and deal with Edward's behavior and his academic and social problems. I would be happy to help with these issues.*
 5. *Edward should have his weaknesses explained to him so that bit by bit he can learn strategies to strengthen or circumvent them. I would suggest cognitive therapy (work with rules, logic, abstract reasoning) once weekly for the time being.*
 6. *Sports, drama, art and other extra-curricular activities should continue to be promoted as they are an important means of maintaining and developing peer relations, self-esteem, confidence and general motivation.*
- Please let me know if I can be of further help.*

Edward started fifth grade on September 4, 1995. The annual school fees were 7'900.- francs per year for Edward, but because his father was working for another school we got a 50% reduction. This was apparently common practice to give such a reduction. The AI didn't contribute to his schooling at the private school, but they agreed to continue to pay for his psychotherapy with Mr. J. until June 1997. Mr. J. wrote to me in September:

Two months have passed since our last meeting; I hope this period of time has allowed you to observe the effects of Edward's new treatment. I think it would be good to meet again to be able to take stock of the current situation. I invite you to contact me to agree to a date.

We met at some point and, according to a letter dated April 3, 1996, to the AI decided to suspend the psychotherapy treatment. Edward attended his last session with Mr. J. on November 17, 1995.

Dr. M. prescribed Ritalin for Edward and I wrote down his reactions:

<i>Ritaline</i>	<i>Started Wednesday, September 20</i>
<i>Wednesday, Sept 20</i>	<i>In the evening, Edward couldn't get to sleep. Played with Mask Dog and eraser. Played Deminer on my computer – a first! Yelled about the place. Went to sleep around 22:30.</i>
<i>Thursday, Sept 21</i>	<i>Went to bed, but not to sleep until after 21:30. Complained of head-ache.</i>
<i>Friday, Sept 22</i>	<i>Went to Dad's for weekend.</i>
<i>Sunday, September 24</i>	<i>Complained of headache</i>
<i>Monday, Sept 25</i>	<i>Forgot to take pills. Left for school and came back to get them. Bad-tempered. Sensitive to criticism.</i>
<i>Wednesday, Sept 27</i>	<i>Says he feels like he's in a dream sometimes, especially when he's at school, like he's not really there.</i>
<i>Thursday, September 28</i>	<i>Talked to Gayle C. today about hyper-sensitivity. She said that perhaps now he gives himself permission to be the little shithead. He had an argument with David and called him a son of a bitch. Mix – “No, I don't want to do this. Be nice to me.” It's like the layer of pleasing behaviour has been removed.</i>
<i>Friday, Sept 29</i>	
<i>Saturday, Sept 30</i>	<i>Roller skating from 18:30 to 21:30</i>
<i>Sunday, October 1st</i>	<i>Roller skating from 9:00 – 16:00. Came back and did his homework by himself.</i>
<i>Monday, October 2nd</i>	<i>He did his homework as soon as he came back from school. Got angry. Told me he was angry when he wrote. Talked to Dr. M.. Reduce dose from 2 pills to 1 ½.</i>

Edward's teacher, Mrs. Iovino, wrote in his school report on October 4 (translated from French): *Edward has taken the path back to school with enthusiasm. He wants to do well and consequently is working well. May he continue!*

She also told me, at some point in time, that she didn't mind if he didn't take the "head medicine", that she could cope well with him when he started to be distracted. She found that he would happily go to a room by himself and work for a short period of time.

For the October school holidays, we went to Martinique in the Carribean with the children. We rented a house near Sainte-Anne with a swimming pool. One of our memories of Edward is him climbing up on the wall next to the swimming pool and shouting, "Look, Mummy, look" and jumping into the pool. With the jetlag he woke early in the mornings around 5, and jumped into the pool.

In his school report of November 23, his teacher wrote: *Little by little Edward has installed himself in his school work, of which he understands much better the rules. He willingly asks for more explanations when he is in difficulty. It is good! The next objective is that he has more confidence in himself.*

1996, the year Edward did well with Mrs. Iovino at Ecole Farny

I received a letter from Mrs. T. dated 11 January 1996, in which she wrote: *On December 15 1995 I received 810 SF from Mrs. Lindley for my bill dated 22 September '95 for a total of 1,620 SF. On December 20th I received a letter from his father who questioned the final amount due. It is difficult for me to understand why this question is being raised for the first time three months after the bill was given.*

In our first session on 15 August '95 I explained in detail how I proposed to proceed. I mentioned that my fee was calculated on an hourly basis. His father, as a psychologist, can appreciate that before one sees a patient it is impossible to know how extensive the assessment will be. A psychological neuro-pediatric developmental examination – such as was given – is not identical for each child. Edward was given a total of forty four standardized tests. Behaviour scales were analysed, personality tests administered, social history, school comments and liaison with his medical doctor were also taken into consideration. All this information was analyzed and a detailed report with recommendations was written. I discussed my bill with you on September 22 '95. I explained that the assessment had been more extensive than usual because of Edward's considerable weaknesses. I also mentioned, at this time, that I had spent six hours more on Edward's assessment – for which you were not billed.

Edward is a child in great need. I do hope that you have followed up on all of my recommendations; medication, extra language therapy, psychological counseling for Edward and management techniques for parents and school. Based on extensive research, this multi-modal approach is highly recommended by Harvard Medical School and other outstanding medical centres in the USA. A child with language development problems, attention deficit disorder and a very damaged self-esteem (stemming primarily from his language and attention weaknesses) needs help on all fronts. If he does not receive it, his future can be very compromised indeed. You are among the very few parents who have not kept in touch with me after an assessment. I am concerned for Edward and would be very interested to know the support he is receiving. I expect to receive the outstanding amount on my bill of 22 September '95 for a total of 810 SF within fourteen days.

I replied immediately the following day, January 12, 1996:

Thank you for your letter dated 11 January. I understand your concern about the question of the bill. I have paid my half of the bill – as was agreed with his father after our first session.

I understand little about the complexity of the assessment and the results described in your report, but I am not a psychologist. The important finding for me was that Edward can be helped.

The reason why I have not kept in touch with you is, primarily, because you did not acknowledge what I was doing for Edward when I told you of his progress. It was as if you did not listen to me.

Edward is doing well at school. His teacher is very pleased with his progress. She feels that the “d  clic” has taken place. He does his homework without being reminded. He says he enjoys going to school now. He is making firm friends. He is able to understand the consequences of his behaviour. He gets along better with the adults who take care of him.

I have established a number of ways of working and living together based on my extensive reading. We have a reminder system for chores; we have a reward system for when he asks for what he wants, we have one punishment, i.e. confiscating his roller skates, for not obeying the rules.

With Dr. M., we have established the correct dosage for his medication. He is not going to psychotherapy. He does not want to go. He has very supportive, aware adults around him who can listen to him.

He is not going to speech therapy for the time being. He will not go to your recommended person because of the travelling involved. He will go to someone downtown Geneva who he can rollerskate over to, at a later point in the year. He was enrolled in a number of activities which he has decided to drop. He gets home from school at 4:30. He has 30 minutes for a snack and unwind time, one hour for homework, one hour of playing or watching TV. Then it is 7:00 and we have dinner together and he is in bed at 8:00. He actually enjoys the freedom of being able to decide what to do with his time – on the spur of the moment. He has school on Wednesday and at lunchtime on Wednesday he elaborates a great plan of activities for his “free” afternoon.

You say, “I am concerned for Edward and would be very interested to know the support he is receiving”. Let me say this: Edward spends 260 days of the year with me. I am the person who is in charge. I made a career and life choice three years ago to work as a freelance training consultant, and to earn less than before, so that I could devote more time to my children’s upbringing. I am in the final stage of three years of psychoanalysis. I have trained as a co-counselling therapist. I am a responsible, courageous and positive mother. As you know what it is like to live with a child with weaknesses such as Edward’s, then you realize just how important those characteristics are. I have learned that at the end of the day I am the person who bears the responsibility of what happens to my children totally on my own. I have learned that people who carry titles such as psychologist, doctor, speech therapist and teacher may have opinions, but that they don’t reduce the weight of responsibility upon my shoulders. I pay to hear those opinions – and I choose to do what I want with them. I’d like to remind you that I was the one who kept on researching Edward’s case and searching for alternatives.

I think Edward deserves to have such a loving, devoted mother. My parents and others think he’s lucky to have a mother blessed with such patience. I now tell such people that if they want to give their opinion on what he needs most, then have to spend at least two hours a week regularly with him.

If you want to know more about my character and life, ask Dr. M.. She’s known me for as long as Edward has been around. It was on her recommendation that I consulted you. She is supportive, helpful, cheerful and practical.

Thank you very much for your assessment and your recommendations. They are valued and helpful. I appreciate your concern. I will not be asking for your assistance in the near future. Once again, I regret the mishandling of your payment. I do not wish to be reminded that his father has not paid. I have already recommended your services to an acquaintance, P.P. I will not hesitate to do so again.

Mrs. T. wrote to me on January 22, 1996:

Thank you very much for your long and detailed letter, I really was glad to hear how well everything is going for you and Edward. I also want to say that I am sorry if you got the impression that I thought you were not a good enough mother. Quite the opposite! Please remember my previous letters were addressed to both you and your ex-husband. I am starting a support group for parents (see enclosed). I am sending you an invitation – please come if you feel like it. We might be few, but it is a start. Let me know. (I hope you do not mind my not inviting his father at this time).

I wrote to the school in January asking them to send John a bill for half of the tuition and half of the after-school homework class.

Edward's first school report of the year in February, 1996, stated: *Edward is becoming more and more responsible for himself and his work. His work is becoming more meticulous, and more committed to progress. It is good!*

After a week of skiing vacation with my parents, I wrote to them on March 8, 1996:

I realize that I have organized my life and my working style so that I don't get overtired too often. I have time for the kids. I have time for Jean-Luc and cooking supper. In fact it hit me that I have set my life up so that I don't have to ask anyone for help. I have found a replacement for Nancy, a very nice, friendly Portugese woman.

I am glad we talked about the stress we create during family visits. I feel you appreciate all of us with our quirks and our talents. I also appreciate that you came out, especially Mum, with what you felt and you said it somewhat forcefully. It always stuns me when you talk to me forcefully and so I shut up. I have a memory of talking back to you once and getting sent out of the house. I

also remember being told, "stop making a fuss, why do you always make a fuss?" when things were out of control for me and I cried or got angry. You said, the other day, that you used to get upset watching 'the way I let myself be treated' by John. I think I let myself be treated like that for so long, before it occurred to me that what he demanded was incorrect, because I was brought up to take other people's needs and wishes into consideration, to give them more importance and if I was not feeling ok with it, "too bad, just make an effort. Don't make a fuss."

His school report dated April 30, 1996, stated: *Edward is getting back on his feet after having let himself go in a sort of rejection of all work ... (after a weekend). He is becoming willing again, friendly towards others, and doing his school exercises with more rapidity. May he continue!*

Edward started seeing a Jungian child psychologist, Berthe, on March 22, 1996. He had seen Dr. M. earlier in the month and said that he would like to have someone to talk to, preferably a woman.

I wrote to my friend, Rose on June 10, 1996:

Beatrix and Edward are well. We are going through a stage of tough mother and setting limits - which I personally hate - but they seem to accept it and even enjoy it. I can't quite figure out the pre-adolescent mind. I can't quite understand why they enjoy being ordered about. Still we are spending time together in a different way: more structured.

Jean-Luc and I need to spend time together as well - it seems like it's been a long time since I dwelled on how happy I am.

At the end of the school year, Edward passed with an average mark of 4.25 out of 6, and graduated to 6th grade.

Berthe wrote to me in August to say that she was moving to another office and would like to fix a regular day and time each week to see Edward. We agreed that he would go on Wednesdays at 16:00. I hired a young man, Didier, to spend Wednesday afternoons with Edward and to take him to his sessions with Berthe.

She wrote to me on October 16, saying that I should tell Didier to be on time because Edward was arriving late. She wrote: *I have told Ed that I was going to write this note to you. I think it must be difficult for him to come here –*

something that I have lots of comprehension for – and the person who accompanies him must be firm.

John and Judith married on Friday, September 6, 1996. Edward and Beatrix attended their wedding.

Edward started taking scuba diving lessons with his father in September.

In September 1996, I wrote to John:

As I have had no response to my letter, I have taken the following steps:

- 1. I have called the Guardianship Court in Geneva to find out what is the procedure to obtain that the judicial agreement is adhered to. I have to write to them to ask for a meeting which is then considered an official complaint against you.*
- 2. I informed the children of the judicial agreement and their rights. I explained to them that you are obliged to:*
 - a. Pay towards their cost of living;*
 - b. Have them for half of the school holidays and two weekends a month.*

I have told them you have said that you would not have them for two weekends out of each month for the months of September through December. Based on this, I gave them the choice of

- i. Leaving things in this way although it is not legal nor fair to them*
- ii. Deciding not to see you at all*
- iii. Taking you to court.*

They have said that they would like to see you as often as agreed upon in the judicial agreement and if this means that we (you and I) have to go to court, then I should go ahead and write to the court. They want to be reassured that you will not go to jail, and that they will not have to appear in court to witness against you.

If I do not have your response with new dates by September 27, I will go ahead and write to the court.

I called the Guardianship Court on September 30, 1996, and was told that no information was given over the phone, so I wrote the following, translated from French:

Following my telephone call, I'm writing to ask you for a meeting to clarify the process that I should use so that my ex-husband will respect the rights of visit that were stipulated in our divorce agreement, which stated that he had visiting rights with the children for two weekends per month and half of the school vacation. Their father has decreased steadily the number of days per month and the school vacation. What I would like to know is what are the children's rights in maintaining these visits, and what process we need to follow to obtain a mediator.

I received a letter back saying that the father had an entitlement to have the children to stay on weekends and holidays, but that he was not obliged to exercise his entitlement.

In my journal I wrote on October 12, 1996:

"Received a letter from the Tribunal tutélaire yesterday. I have to 'umstellen mein Kopf' (turn my head around). John has a right to the children, but no obligation to take them. So now I have to imagine what this means. I have the right to 'put the children at his disposal' when I want. So what is it that I want? Jean-Luc says most mothers don't want their children to go the father and I am the opposite. I believe when one has a right, then one has a responsibility. Meeting with Mrs. S., the social assistant of the Service de la Protection de la Jeunesse on October 14.

I received a telephone call from Mrs. S., a social assistant of the Service de la Protection de la Jeunesse (Youth Protection Services) who said she wanted to talk to me about the children. I told her that it was no longer necessary, that I had received a letter from the court telling me that John had no obligation to exercise his right to have the children for visits. She was at first rather dry and impatient with me on the phone. She and I were obviously at cross purposes. She told me that John had written to her and asked her to intervene and that she had to see me. We fixed a date for the meeting.

I went to the meeting and she asked me to explain what I held against John. I said to her that I had misunderstood that he had no obligation to take the children, and that I was not allowed to complain. After again talking at cross purposes, she gave me a letter that she had received from him complaining that I had moved to the red-light district of Geneva, where my son was talking to prostitutes in the street, and a number of other reproaches against my parenting.

I wrote in my journal on October 20, 1996:

No, John doesn't want custody. He does have two pages of reproaches towards me (and Jean-Luc) for all kinds of things. The World has done him wrong – the judge has taken away his children, his ex-wife mistreats him – oh woe is he! Had an extra session with Evy (my therapist) to keep my head above the shit. She says he must be in a really bad state. She tells me, be strong towards them all and show that you cannot be put down by such stupid slander.

Mrs. S. from the Youth Protection Services came to meet Beatrix and Edward on November 1.

I wrote in my journal on November 3, 1996: *Madame S., the social assistant, came to see Beatrix and Edward on Friday. Edward wants a meeting with his father. Mrs. S. will mediate the 'droit de visite' (right to visit).*

This was Mrs. S.'s proposal, that she would mediate the children's visits to their father. Jean-Luc was so helpful during this time. He said that we would show how grateful we were to have the children for all the weekends, that we would show them that we wanted them to be with us.

I wrote on November 24, 1996:

I must not allow myself to talk to John. He talks and I don't want to be aggressive and so he has the satisfaction of being listened because I don't contradict. And I'm always left with a load of his shit. Well, put it on the roses so they'll bloom!

I guess it's really bringing up the differences in opinions and beliefs between us. I really don't agree with what he says. What a load of baloney presented in such complaining terms. Oh well dwelling on it doesn't do anything for me – think I'll make chocolate chip cookies instead.

1997, the year Edward went to private middle school

There were three two monthly schedules written up by Mrs. S. On the top of each it, she had written *Organised with the agreement of the parents and the children*. Beatrix spent Tuesday nights at her father's, and Edward spent Wednesday nights during the months of January and February. At the end of each two month period, there was a meeting with the children to take stock of

the situation. Starting March, Beatrix had lunch with her father on Tuesday rather than going to stay with him.

On February 3, 1997, John wrote to my father. I don't know from whom I received a faxed copy of the letter. In it he writes: *Communication channels with Kate have broken down. For the arrangements concerning the visits of Edward and Beatrix we are passing through a state-run organization (on my own request). The children are now spending one night every week with me and one week-end a month. We are trying this for a couple of months to see how it goes. I personally feel happier because I feel more part of their lives and less of a "weekend activity". On the other hand I am very concerned about Edward, the whole situation is hard for him to live. I fear that the environment he is living in is not appropriate and that he needs much more stability. Maybe I am wrong and I am sure that Kate is trying her best. Nevertheless he obviously needs more of my presence and I hope these arrangements can help.*

I wrote to my parents on February 27, 1997: *We had a two hour session with the social assistant this morning which wore Jean-Luc and me out. We're making progress. She said she has told John to stop harassing me.*

Around this time, I asked Mrs. S. if she had finally made a decision about whether she would have my custody revoked. I had talked to a close friend, Françoise, about how difficult it was to be constantly worrying about it, and she had encouraged me to bring it up with Mrs. S. Mrs. S. seemed so surprised, and said that that decision had been made in November. There was no question of revoking custody. She said that she thought she had been clear about this to me. I remember thinking why hadn't I been able to hear that.

In March 1997 I consulted Ms. P., the lawyer who had taken care of our divorce, and asked her to start proceedings against John to increase the contribution to the children's maintenance to pay for vacation activities when he didn't take the children, and to receive 50% of Edward's school fees until the end of his education. I told her that Mrs. S. was now taking care of the visit schedule, and that I did not wish to make any changes about his visiting rights. I wrote: *I have also informed Mrs. S. that John will not be invited to attend any more school meetings about Edward's future because he takes each opportunity to insult me or reproach me. He has thereby lost his opportunity to voice his opinion, a right that I gave him in the past.*

On April 8, Ms. P. wrote to John to inform him that I was going to take him to court for the increase in contribution. On May 9, she sent me the drafted request for the modification. I wrote to her on May 25:

I have decided to delay (perhaps renounce) the request for the following reasons:

- *Mrs. S., the social assistant, has convinced John to take the children for four weeks from June 28 to July 25. She has asked him to prove his responsibility and to take full care of them.*
- *If John receives the order to appear in court and to pay an additional sum of money because he doesn't take the children very often, I risk putting my children's vacation at risk. They are so happy to be spending four weeks with their father. And I will find myself with two very disappointed children and will have to find them something to do for four weeks.*
- *I will give him the enrolment form (and ask for the half of the school fees) for the Benedict school for Edward. If he refuses, then I will have the proof that he is avoiding any contribution towards Edward's school fees for the request for the modification.*

I hope that you understand that I want the best for the children and they are having a hard time with the misunderstandings between me and their father. Please stop all further proceedings, and send me your invoice.

During the school year Edward had been taking African dance lessons, and in June he took part in a show. His dance teacher, Jana, wrote to him at the end of the school year: *I heard that you had an accident and hurt your knee. A pity that you couldn't come back to class after the show. I know you had a lot of pleasure in doing the show and bravo for your work.*

I wrote to the paediatrician, Dr. M., in November about this period: *Edward stopped taking Ritaline in February or March 1996 with the support of his teacher, Mrs. Iovino without any deterioration to his school work. I think we saw each other then, and Edward said that he wanted to start psychotherapy again. He is still seeing Berthe.*

Edward made much progress with Mrs. Iovino and Berthe, to the point where my partner and I said that he had become a normally difficult adolescent. He

passed sixth grade and we did not worry too much about him starting seventh grade at the Benedict school, the secondary school of the Farny school.

E-mail to Rose on September 2, 1997:

Apart from that, I have had a journey through the tunnel this summer. Hitting 40 was depressing.

Edward was very ill in the summer and had three accidents - which mucked up our vacation plans. I have laughed about twice in the past ten weeks - and once was with John , so you can imagine how bad things have been (oh, more laughter). Have managed to stick with Jean-Luc throughout this time which deserves a warm pat on the back.

Edward had an accident during the day out with the school in June. He tripped on gravel and needed 9 stitches in his left leg. He had a second accident early August where he dove into the swimming pool where there was only a depth of 50 centimetres, and got whip-lash. A third accident at the end of August happened when he tripped on gravel and had 6 stitches in his right knee.

Edward started at the Benedict School on September 2. It was a logical step seeing that it was the secondary school attached to the Farny School. I was worried about him making the change from one teacher to a different teacher for each class, but the school had reassured me that they helped the children. I was even shown a workbook to help the children organize themselves and adapt. On September 19, with the help of Mrs. S., I agreed to John's proposed schedule. He didn't take the children for a weekend during the month of October, but saw them during the week. In November he took them for one weekend, and in December he had them for the two week vacation at Christmas. I had a telephone call from a mother of one of Edward's schoolmates who told me that Edward was skateboarding down the road outside the school. I checked it out and told Edward that he wasn't to take his skateboard to school.

On October 15, I received a registered letter from the school. The director wrote: *Edward's attitude and behaviour in class towards the teachers and the school is unspeakable. He is not able to make the difference in the way he talks to his classmates and the teachers. His vulgar language is inadmissible. There is not one day that passes when Edward is not sent out of the class and punished by the director. We have to ascertain that it is impossible for us to*

teach him any subject. This is why, we would like you to call us so that we can fix a meeting so that we can take a decision about his future.

I called the school and followed up with a fax the same day. I wrote:

I would like to clarify and confirm a few points:

- 1. Edward will remain at school until a more appropriate solution has been found. I have already started looking.*
- 2. If Edward is expelled from class, he will be sent to another classroom where he will remain until the next lesson. If you wish to expel him from the school, please let me know before he leaves the school building. If you cannot reach me, I do not want him to leave your supervision.*
- 3. Edward can leave the after-school homework class as soon as he has finished his homework without me being informed. He does not have to wait until 17:00.*
- 4. I would like you to keep me informed of his “stupidities”. I wish to support and help him over his difficulties. I do not want him to become the scapegoat. For example, it was not Edward who made his classmate eat cat biscuits this morning, but Alex. Edward excused himself to the girl. I find it unfair that Edward is held responsible while Alex’s acts go unnoticed.*
- 5. I do want to find a solution for your well-being, and that of your teachers, for the current situation that became unbearable, without me being informed, but I would like to have the necessary time to find the right solution.*

On October 17, I received his school report for the first period. The six different teachers all said more or less the same thing. Edward was talking too much, not paying enough attention, not working quickly enough. His average mark was 3.05 out of 6. The director wrote: *The school is not adapted to deal with Edward’s difficulties.*

On October 19, Edward had an accident. I wrote to the pediatrician later about it: *He held on to the tourist train, in between two wagons, on the quai, and fell over. He was very bruised and taken to hospital where he stayed under observation for 24 hours. After that I told him that he was to start taking Ritaline again because I was too worried about him.*

I received a letter dated October 21 from the director who wrote (translated from French):

Your letter does not transcribe exactly the content of our conversation of October 15. There has never been question of expelling Edward from our school from one day to the next. On the contrary, the discussion was about our acknowledgement that after having been in the full time care of Mrs. Iovino for the past two years, Edward is so disoriented in 7th grade with 8 different teachers that he cannot manage.

It is in a constructive spirit for the future of your son that I proposed other solutions, such as the Passerelle school, which seems to me to be more appropriate for Edward's development. It is neither a form of bullying nor a punishment.

On October 30, the director wrote another letter:

Following my letter of October 21, I confirm that we have kept Edward until the end of October so that he did not find himself suddenly out of school. During the few school days that have followed, he has continued to use extremely sordid language and I had to confiscate a pair of handcuffs, and all the attitudes previously noted have not changed. It is therefore in his interest that a solution be found so that he can start school next Monday somewhere else.

I went to see Dr. A. to talk about it on November 4. Edward started on November 5 at the Passerelle school. On November 7, in my letter to the pediatrician, I wrote:

My partner and I are going to see the school after two weeks of trial, next Friday. I want to discuss with the director and the pedagogical supervisor about Edward starting Ritaline again. He doesn't understand why he has to take it, he says it is because he is stupid. I would like to talk to you about it.

E-mail to Rose on November 7, 1997:

I took Beatrix and Edward to Marrakech in Morocco for a week's vacation. Edward has been through a really tough time at school and was kicked out of school. Jean-Luc and I have found two solutions, one of which he is trying out this week. Imagine a school where the teacher doesn't take notice of kids saying "shit"! it sounds a bit like Summerhill. Another solution is a weekly boarding school for studies and sport. I think they wear the youngsters out at sport so they are too tired to fight the teachers..... Needless to say, countless cardboard boxes have entered the home whole and left in little pieces!!!

E-mail from Rose on November 11, 1997:

Sounds like you have got it much tougher right now. Edward is fortunate at this point having you and Jean-Luc battling for him - keep battling, and laughing...

E-mail from Rose on November 18, 1997 :

Hope you're surviving whatever it takes to get Edward settled again. Aletha's coming to Europe next May. I'm trying to see if can get something organized in Britain. Found interesting possibility in academic interest and courses connected with parenting skills at De Montfort Univ. Leicester. However so far haven't got to speak to woman who's the queen bee.

E-mail to Rose on November 20, 1997:

I was finally feted on October 17, 3 months after my actual birthday. I took 30 people to see Thalasso Blues, a play written and played by Francoise, who works with me. We then went home to dinner which Jean-Luc cooked. I made a speech and we had other speeches and games. And 30 people sang Happy Birthday which was wonderful, and I've finally accepted being 40!

Edward is in a new school which has a "learn to learn" approach and seems really cool. He is happy. I'm still quite tense about it, but I am in general very tense these days - angry, not trusting others, feeling lonely and stressed, having fainting, sick spells. You name it! oh, forgot: no energy.

E-mail to Rose on November 28, 1997:

Edward is being squeezed into submission by his school - and liking it. I have discovered an incredible amount of anger of mine towards his father. Is it a step further to discover that one is incredibly blocked by something like anger? It seems like I have to decide to go down this path and work on it - and there is incredible resistance to spending energy on anything which has to do with John. John has decided that he can pay one fifth of the school fees and the social assistant glibly assumes that I should pay the rest and when I get upset, tells me to "put my fist in my pocket". Jean-Luc is absolutely fascinated by it all - so we are looking at it very intellectually. The objective is fixed: I do not want to be hurt and disappointed by him anymore. It seems that I have this "incredibly" unrealistic expectation that he could be a partner in parenting.

I am currently working on "I'm delighted" he can't have the children next weekend as planned cause it means that I can spend more time with them. Next step is to say "I'm delighted" to pay four-fifths of the school fees.

I find myself so terribly alone - do other women feel disillusioned by the lack of parenting done by the "fathers of their children"? I hear complaints about fathers coming home late, staying late at work, working on weekends, etc. It seems to be a taboo subject: partners in parenting.

Jean-Luc is being great with Edward.

E-mail from Rose on December 1, 1997:

Re-reading your e-mails, I have a strong reaction - wish you and Jean-Luc lived nearer, or in Scotland so it was easier to share and enjoy your company. I do appreciate your down to earthness and persistence, and ability to laugh. In my experience anger is difficult to work with - hard to not rehearse aggressive stuff. Using contradictions does seem helpful, if lots of energy put into saying and still including box tearing. Alternatively sometimes it is necessary to get really nasty symbolically, like knifing face on cardboard - usually needs safe counselor to do it with. I think it's about the need to get in touch with the full depth of the feeling, and we don't want to do this, but stopping short doesn't really crack the underlying stuff.

The other thing that strikes me about getting angry with John is this is totally justified - that his behavior provides repeated obstacles in the present. I think it's highly appropriate to be very angry that he isn't doing his share even in minimal view of what his share is. [And looks like the social assistant is well brainwashed to favor men].

It sounds hopeful that Edward is now in a school where he can find a place for himself with respect, and get to develop.

Edward's first impression on his teacher at the Passerelle school: *Edward is an agreeable pupil who likes to invest himself in his work. May he continue doing well!*

His school report for the first period of evaluation from November 17 to December 5 stated: *Edward must put in a big effort in his behavior and*

applying himself to his work. He should take advantage of study time to do his homework. His behavior was graded 4,5 out of 6, and his work 4 out of 6. Jean-Luc co-signed the report with me.

1998, the year Edward started boarding school

For the following period, up until January 23, 1998, the teacher wrote: *Edward is not working in class and disturbs his classmates continuously by making funny faces. Sometimes he makes an effort. I hope that his work grade improves by the next period.* His behavior was graded 3,5 out of 6, and his work 0. He had retention on Saturday, January 31, from 9:00 til 11:30. Afterwards he told me that he had enjoyed being alone in the classroom. He could concentrate better.

By March 13, both his behavior (5) and his work (4) had improved and the teacher wrote: *Edward has made progress. He must continue his efforts during the third trimester and work more regularly.*

On March 16, I wrote to John:

We have had another crisis with Edward. He had a very good week at ski camp, but flipped on his return. I was violently insulted and hit. He said he wants to go to boarding school and I am going on Thursday this week to see Maya Joie with Jean-Luc. I and Edward are being supported by Berthe and the school director who was present at the outburst. Having spent the weekend studying Piaget, I can now understand what he meant by egocentrism and how it applies to our son!!(see footnote).

On March 23, I wrote to John again:

Edward is in very poor shape, suffering from not having you around and I am having an extremely hard time. I have asked Mrs. S. to intervene and she will come to see him. I have been to visit the boarding school, Maya Joie, and will take him up to the school to see if they will accept him.

John replied on March 24: *I am extremely sorry to hear about Edward. Maybe Mrs. S. can be of some assistance in this, however I also support you in your decision concerning the boarding school. Edward probably will benefit from the structure they offer and maybe less prone to feeling that either of us has abandoned him.*

My friend, Eva, wrote to me on March 23:

Sorry to hear you're going bananas again with Edward. Boarding school, huh? Have you considered a religious order? A stone-breaking crew in South America? A pig farm in China? What that boy needs is some sense knocked into his head, but lucky for him neither you or I are partial to head knocking. Can't you apprentice him off to some worthy artisan so he learns a trade and you don't have to worry about him eating when he's grown up? Just kidding... Where's the school? What's it cost? What's he think of this?

No, I'm not tired being a mother yet. But I don't have half the problems you have to deal with with my kidlets. Yet.

I wrote to my sister on April 20: *My major decision concerning Edward is that he will go to weekly boarding school in the Valais as of September. Having a hyperactive, attention-deficit adolescent is very draining and I have been fighting my feelings of guilt because I cannot cope anymore as well as I could, in the face of adolescent resistance. I talked to Mum the other day; there are definitely similarities between Matt and Edward. Maybe that is why Matt is so good with Edward. He says, "Come over here, mate, stop bothering your Mum and sit next to me" and Edward responds well. In fact, what Edward needs is a male role model who orders him around a bit. As his psychotherapist assures me, in the words of Winnicott, "there is an end to mothering". So Ed will go to a super school, run by male teachers, with a good reputation for getting hyperactive kids off Ritaline and on to sports. They have two hours of intensive sport per day in the programme. Edward made the request to go, with a certain amount of difficulty for fear of hurting me, but we have talked a lot and he will go in July for three weeks summer camp at the school before starting so that he will know what to expect. He is terribly behind in his school work and will have to re-do seventh grade. However I feel confident that I have taken the right decision. Now I just have to get used to it His Dad is supportive of him going to boarding school and he will spend alternate weekends with him (usually spent fighting and shouting at each other, so I hear).*

I hope this will also give Beatrix a bit of breathing space at home without him during the week, especially as she goes on to Cycle d'Orientation (junior high) in September. She is an A-student, very studious and very quick. We will see how it goes when the standards of work increase at the Cycle - she is an anxious student which means she also tends to worry a lot about achieving.

Right now, she's top of the class, but that still doesn't seem to relieve the internal tension. So I know I will have to be available for her as well.

Extract from an e-mail to my friend, Rose, dated April 27, 1998:

I am very much in the process of visualizing happier days with my two children after a miserable Easter break, where they didn't want to do anything I suggested but complained about being bored.

Jean-Luc and I have bought a chalet in the mountains. It was a bit like getting married what with all the papers to be signed and so on.

Edward and I have reached agreement on his school future - and he will be going to weekly boarding school as of September - and the best bit is, that they have a great track record with getting kids off Ritaline and on to sport activities.

In May I wrote to John:

Edward has been accepted at the Maya Joie school by Mr. R., the director. He has talked to me of a foundation that can help finance the tuition fees when Edward has to send his school report. So I haven't said anything about how much we can pay. Mrs. S. says that we should talk to Mr. R. about what we can pay together, rather than separately.

I am looking forward to having two weekends "off" this month and I'm sure you are really looking forward to being with your kiddies again.

Edward asked if his friend, Alex, from the Bénédict School, could come and stay with us for the weekend. We picked him up on Saturday morning and his mother asked me if it was alright for him to bring his air rifle that he had packed. I went cold, and said that it was not. The last thing I wanted was these two boys charging around the village with an air rifle shooting at birds and cats.

On November 27, I wrote this account of the weekend for a lawyer:

From Saturday, June 20, at lunchtime until Sunday, June 21, at 21:00, Alex GG, a friend of my son Edward, came to spend the weekend with us in our chalet in the village of Huémoz. On the Sunday evening just before 18:00 the boys asked me if they could go for a bike ride. I let them go, asking them to be back by 18:00. They came back at 18:30 and we left shortly afterwards for Geneva.

When we got home, I received a telephone call from Mr. J-D.B. telling me that my son and his friend had damaged a bus and a digger, which belonged to his company. My son admitted to me that he and his friend had done the damage. I immediately called the parents of Alex. His mother assured me that her husband, director of the R. watch company, and herself would inform their insurance company, where they were insured for civil responsibility, and that they would pay half of the damages.

On my side I announced the case to my insurance company. They agreed to pay the amount of 4'250 francs, representing the half of damages fixed at 8'500.- francs.

I hit my son, Edward, with my belt across his legs that evening. I was so furious at having been deceived by him and that brat, Alex. He went to school the next day with bruises on his legs, which he showed to Alex. Alex laughed and said that his parents thought it was a joke. They refused to pay their part of the damages, which is why Mr. J-D.B. had to take a lawyer. The following weekend I took Edward back to the village, to see the damage with Mr. J-D.B. He was so upset, he had tears in his eyes. He told Edward that the bus was a collector's item, that his father had bought it many years ago, and that he had been planning to drive it in a rally that summer. Edward spent the day cleaning out the broken windows. I spent many hours talking with a lawyer who was a friend of ours, to see whether my civil responsibility insurance should pay for this and what arguments I had to present. I found myself describing my child as an 'out-of-control' boy.

He finished the school year with an average mark of 3,6. The school director told him that he had passed seventh grade, but his school report stated that he hadn't. The teacher wrote: *Edward has achieved mediocre results this year. In order to support his efforts, his average marks were over-evaluated. Edward however does have possibilities but he doesn't give himself the means to do quality work. He has made great progress in his behavior and was well integrated in the class.*

I wrote to my parents about the children going to England to stay with them. *Edward is away until Saturday, July 25, at the summer school of Maya Joie and I need one day to clean him up and get him off so they can't come before. Life is full of highs and lows at the moment. Beatrix won first prizes in her jazz and classical ballet, and last night was awarded the prize for 'best pupil of the her*

class' in front of 1000 people at her graduation ceremony from primary school. She has passed her last year with an average of 5,3 out of 6. We know that I have the two extremes – Edward has 'passed' 7th grade which is not quite true. He flunked maths royally. He has also had another accident and was caught committing vandalism. So his week away with me has been 'confiscated'. He's off to Maya Joie on Sunday which is just as well because I am in terrible shape. I am sure Maya Joie in the mountain air will do him a world of good. Just hope they keep him on a short rein and get him to take a bath every day.

Edward attended summer camp at the Maya Joie school that summer. His school report stated: *Edward's school situation is worrying. He did not show much interest for the French and maths courses. He has considerable difficulties. Lazy, he looks for all the ways he can to run away from the requirements of school (sickness, toilet, etc.). He must absolutely change his attitude towards the school. If he does not take this seriously, and if he does not want to work, he will achieve nothing.*

Edward found an outlet for his well-being in the sport activities. He participated well.

In his daily life, Edward can show anguish and anger. However, he also often shows a lot of kindness.

I wrote to my parents in the month of July:

John is not against the idea of the children flying over but is not paying for their flights. They will see him for one week and three weekends out of their four week stay with him. If they come to you, they would miss one weekend.

I have booked a flight to arrive on August 12. I will come over to you on August 12th and have to be in Durham on the following Saturday, the 15th, by 16:00.

By the way, I was invited to dinner by Jean-Marc (former boyfriend) on Wednesday night – keeps old Jean-Luc on his toes – who told me that our relationship was a turning point in his life. I keep thinking that the Americans call it a watershed. Apart from telling me how many mistresses, kids and hotels he had, he also told me that he loved me just as much as 18 years ago, walked me home and sent me flowers the next day. I told him that we would have really made a catastrophic couple, besides which, at 42, he is fat and old-looking. Men like that keep me at home with my man. Hope I made you smile.

One of my close friends, Eva, had an aneurysm at the end of July and was hospitalized in intensive care. The children were at Leman College for summer camp and I spent visiting hours with her every day. I was with her when she died on August 7 in the evening. She left two daughters, Léa and Zoé.

My friend, Rose, wrote to me: *Your e-mail sparked off all sorts of thoughts. Sadness which encompassed Eva's life and death as you describe it, you lacking support to talk through and unload the experience, and something about how much institutions and cultures make it hard to put people and their real needs first. Also something about how people observe coping skills and assume it's ok for you and don't want to know that it isn't.*

I had started studying psychology with Open University in February and attended my summer school mid-August. Rose wrote: *Hope you enjoy your week in Durham – expect there's lots of jolliness and interesting people.*

Edward started his school year at Maya Joie on September 1.

On September 2, I wrote to my sister:
Beatrix started big school on Monday. She has 5 kilos of books to schlep with her almost every day. Of course she is sure that she will not make it. Anyway she is in the same class as her best friend, Sabrina. She is in the Latin section - eagerly supported by my partner Jean-Luc who also did his Matura in the Latin section.

I took Edward up to boarding school yesterday. He was quite relaxed about it - until he saw that he has to redo seventh grade - he is now in the same grade as Beatrix, but we are keeping quiet about that for the time being. Beatrix kissed him good-bye! a first! It already seems so strange without him. I laid the table last night for four and then realised that we were only three.

I wrote to my sister on November 9: *Jean-Luc and I took Beatrix to Rome for four days during her Herbstferien (in French, vacances de patates / potato holidays) to inspire her to continue in the Latin section at school. She liked the cats, the pigeons and the lizard. And I liked the pasta, the shops and the Sistine Chapel.*

Edward and I went to Uncle Mike's funeral during his break (unfortunately they are in different cantons so the holidays are different - very practical). Not exactly great fun, but it was nice to take him with me.

I wrote to my sister again on November 17:

I have just ordered Reviving Ophelia from Amazon.com but I must admit the reviews sound somewhat alarmist. There is a French psycho-analyst, Aldo Naouri, (must be Freudian) and pediatrician who has written a very controversial book called Daughters and their Mothers. He was interviewed on TV recently and came across "nicer" than in the book reviews. He said that women have to deal with their relationships with their mothers before they could be "good" mothers. And if they could not deal with it, the fact of voicing one's negative experiences, feelings, perceptions was already a BIG step forward. Because it is not done to say so, one should say it. It was quite interesting listening to him, but I didn't feel inspired to read the book. I have read part of his book on the Role of the Father until I got to the bit where he stated that the Father is the man who the Mother trusts enough to give him the role. That of course gave me an immense sense of satisfaction ... for all the wrong reasons.

And again on November 30:

I finished the book Reviving Ophelia late last night. I found it almost compulsive, but also repulsive in parts. You went to junior high in the States. Was it like that? The thing I did enjoy about boarding school was that I learned that girls could get along, that we could be "solidaire" (stick together, stand up for each other and take personal blame instead of letting everyone be blamed) which was relief after the cattiness of the intercommunity school in Zurich. So thank you for recommending the book because of all the thoughts and ideas it has raised. I think it also shows that no matter how hard you work at being the "good enough" parent (words of Bettelheim), there is also an aspect of self-determination and personal destiny of the child which is beyond us and our influence.

I also realize that something needs to be done about Edward's sexist remarks and that baffles me. He said to me two years ago that he wondered what a man's role is when a woman can do it all by herself, like I can in his view. My reply was to be a partner and to work out a relationship based on real needs. I

told him that my need for a partner was based on love and support for each other.

1999, the year Edward was doing well at boarding school

In my folder I have no correspondence with the school concerning Edward's behaviour. Similar to when Edward attended the Farny School, there was a period of time in which I had no telephone calls that started, "You know what your son has done...." Such a relief! He had a "weekly observations record" that we had to sign when he came home each Friday. He had another evaluation booklet which showed his grades, and had to be signed five times a year. On this booklet it stated that Edward was in remedial class. At the end of the school year, it was written that he would attend seventh grade the following year. He was accepted back at the school. The final bill for his tuition for the year of 1998-1999 was sent on July 12. It came to over 30'000.- francs, and we received a 2'000.- contribution from the school foundation.

I wrote to Mr. R., the school director on September 16, 1999 (translated from French): *I would like to ask for your help around the homework. I agree with your approach to check that Edward has done his homework and to sign it, so that we keep in contact with the school and follow his progress. Only, Edward and I are in a difficult situation. He is currently very aggressive towards me and since the beginning of school the problem of homework adds to the difficult situation. It has become my problem because I have to check and sign it, so I have to persuade, to coax, harass and then threaten Edward to do his homework. Then "he doesn't know" what to do so I get out the dictionary and almost do it in his place.*

In my general distress dealing with Edward who insults me and blames me for all his misfortunes, I have consulted Dr. A. who has recommended a number of practices to free myself from this conflict. Dr. A. considers that Edward can only assume responsibility if I give it to him. So I am writing to ask you if you could allow me not to check and sign his homework, and to let Edward be punished if he has not done them by a retention at the end of the week. Perhaps during retention he could do his homework.

John wrote to me on October 3, 1999: *If I am not mistaken, we had agreed in front of Mrs. S. that I would discreetly contribute 4'000.- francs per year to help you with Edward's schooling in Maya Joie. ... As you know my salary has not*

been changed since 1992 and as much as I fully appreciate the expense you are paying for Edward, I really cannot afford (to pay) more this year. Hopefully, my next job will allow me to make a better effort at helping you, which I am keen to do because I really appreciate what you are doing for Edward and Beatrix.

2000, the year Edward was expelled from boarding school

In the report card dated February 18, 2000, the director wrote: *Maya Joie has reached the end of its competence.*

The house master wrote on April 6, 2000:

Edward is an emotionally disturbed boy, demonstrating rather serious behavioural difficulties. He has a great need to be watched, to be looked at. He is a boy who suffers from poor self-image because he has often been confronted with failing at school.

He likes to mock others but he won't put up with anyone mocking him. However since he has been taking his medicine for his hyperactivity, I can see a slight improvement. Before he couldn't put up with any frustration nor with any severe reprimand. During these moments, he would start having a tantrum saying he was persecuted. He would blame everybody and would swear at anyone in his way. Today, he still gets angry but expresses his feeling and goes away to calm down. He insults less the people around him when he is angry. I find that he has made progress but he needs to soften his character. Apart from that, he is often a very affectionate boy (all the same!)

Around this time, I had started Edward on a special diet that was supposed to reduce hyperactivity and attention deficit. I went to five different shops in different parts of town, and beyond, to buy food without additives and phosphates. I made sure that on weekends he didn't have any additives or particular foods, and on Sunday evenings I sent him off with a bag of food for the week. Mr. R. finally found that even if I was an "overprotective mother", as I had seen him write in Edward's file when he first interviewed us, I was committed to finding solutions that would help Edward's behavior.

I also contacted the neuro-pediatrician, Dr. H., at the Geneva University Hospital, for an appointment. We saw him on March 7, 2000. I asked him to confirm if Edward had ADHD. We spent two hours, mainly with his assistant, telling about many things that we had already told other doctors. The following day he, or his assistant wrote up the report, and sent it to Dr. M., our pediatrician,

and to all the doctors, psychiatrists and psychotherapist who we had consulted. I have not included the full text.

The last paragraph reads:

Discussion

The anamnesis is not typical of the ADHD syndrome although Eduard presents many signs. A number of other disruptive factors have interfered in the evolution of this young man, who currently suffers important behavioural problems. It would be suitable to find an establishment that corresponds to his problems and his capacities, as well as giving psychotherapeutic support. With this aim in mind, we propose to meet the different people who have intervened in his lifetime, before seeing Eduard and his mother on April 18, 2000.

It was Berthe who sent me a copy. I wrote to Dr. H. on April 7, 2000. This is my translation of the letter:

I am writing to you to express my astonishment by the way you are handling the process related to my son. I came to consult you on March 7th with a precise question: "Does my son suffer from ADHD?" and I left without a clear answer. I was told it was complicated.

So it was with great interest that I was able to read the report you established and sent to different "concerned" people, notably [Berthe], asking them to attend a discussion about Edward. I kindly ask you to send me a copy of the report because I feel "relatively concerned". In addition, it seems that you have answered my question in your report.

I am absent for professional reasons on April 17 and 18, and will not be able to attend the discussion on April 18 at 4:30 p.m. Edward's father could attend, but I am the parent with the parental authority and the person who would put in place a solution. I am available on the following days. (dates given). I look forward to receiving your report and a date for a convenient meeting, I send you my respectful regards.

Dr. H. replied on April 14, 2000:

Thank you for your letter of April 7th. I am sending you herewith a copy of the consultation report of March 7th.

I am very sorry if I, with my assistant, Dr. D., misunderstood the aim of the consultation. It seems that we were supposed to confirm or infirm the diagnostic of ADHD, whereas we thought that we should, as is our habit, propose help for Edward who has been in a difficult situation for many years. As you know, there

is no specific test to diagnose the syndrome ADHD. Many elements are found present in Edward, but it is obvious that the difficulties that he has met since his first school years largely exceed the problems of the ADHD syndrome. His problematic is effectively, as we said, much more complicated.

We therefore proposed to meet with those people who know Edward much better than we do, and with your permission we sent them a copy of the report, with the aim of meeting together to try to find the means to help and coordinate the therapeutic and educational measures. This meeting scheduled for April 18 has been cancelled because Dr. A. replied that he has only seen Edward occasionally since 1992 and that he is “outside the circle” and Dr. L. is currently absent.

I wonder if we should look for another date for a pluri-disciplinary meeting, however I remain at your disposal for a further meeting at your convenience, should you wish.

Edward returned to Maya Joie early September. On the day I took him up to La Fouly, I saw Alex and his father who greeted me. I didn't reply. I was surprised. I asked to speak to Mr. R. and asked him to make sure that Edward was not in the same room as Alex.

The first letter I received from the school director was on September 8, 2000. He wrote: *The progress that we started to see in Eddy last spring has not been confirmed by the start of this school year. The effects of the diet don't seem to be as strong. Many times we have had to reprimand him for repeated lack of discipline. We don't have the impression that he wants to change. The worse is that he seems to take a malicious pleasure in provoking his teacher into reacting, and making him stand out in front of his classmates. Last week there were numerous incidents. The situation has become so tense that we are thinking of expelling him.*

This week during the school outing, Edward behaved in the most unacceptable way, using rude language to the teacher who was asking him to stop shouting and join the group. It was so bad that I had to personally intervene and demand his apology. He then “blew up” and went beyond all limits. The most elementary sense of modesty forbids me to transcribe the words he was using to describe his teachers, you his mother, and all the people who are close to him.

In the face of this torrent of insults, I slapped his face and took him away from his classmates. Once he had calmed down, he admitted that he wanted to reintegrate public school in Geneva, that he wasn't sure of wanting to be here. I apologize for my unfortunate gesture of slapping him but in the heat of the moment it seemed like it was the only possibility. I have to admit to you that without any change on his side, Edward's requirements exceed our competence and destabilizes the framework which we have established, even if he is not followed by his classmates. He is putting everyone against him. We find ourselves helpless and are having difficulty in maintaining balanced and harmonious relations with him because he refuses to be helped and liked. I would like to talk to you as soon as possible.

I wrote to Edward on September 13: *I wanted to tell you, to explain to you that I will be angry if you are expelled from the school because*

1. *You told everyone, loud and strong, that you were going to succeed this year of 8th grade at Maya Joie and come home next year. We have talked about this long enough – with Ms. S. (the educational psychologist at the AI) and other people.*

You are not keeping your promise. I won't be able to trust you anymore. Every time you will say, "Mummy, I promise that I will do ..." I won't be able to believe you.

2. *I don't have the time and it is not the right time to help you find another school. If you are expelled from Maya Joie, you have no chance in being accepted in the public school in Geneva. So what will you do? One thing is for sure, that you will be going to see Mrs. S. straight away.*

I will be so angry because you will be taking up all my time and attention and you very likely will find yourself in a boarding school where you will not come back on weekends.

Edward was expelled on September 15. Jean-Luc went up to the school to pick him up and took him to work at a farm for a week. This was arranged by the school house master. The following week we took him to a special educational needs school, the SGIPA, run for adolescents who had not passed their ninth grade. The school had a one year program to help the pupils complete their requirements of the obligatory schooling, and find an apprenticeship. That same week we asked friends if he could come and work with them. He spent two days working with my brother-in-law, Denys, at a printing shop, and one day

working for a friend, Bernhard, assembling watch pieces. We arranged for him to start seeing Berthe again.

B. Chapter 5: A new diagnosis – from the end of 2000 to 2005

The end of 2000, when Edward was diagnosed with Klinefelter syndrome

In October for the autumn vacation, I spent a week with Beatrix and Edward and my parents at a Club Med hotel in Ouarzazate, in the Moroccan mountains. During the week, Edward spent most meals sitting and chatting with other people. One evening we were told that two French actors, Gerard Depardieu and Christian Clavier, were coming for the special dinner. We were told that it would be best if we waited until 19:30 to go for dinner, and that we should not disturb them by talking to them. Edward went to see them immediately and started talking to them. They told him they were shooting an Asterix and Obelix film nearby. At one point, Gérard called over to our table asking Beatrix to go and say hello. They were so pleased.

My sister wrote to me on October 14, 2000:

Anyway I heard through the grapevine the usual Lindley family communication, that Edward had to leave his school and I wanted to express my sympathy. I know you were working so hard to change things for him and I am sure this must have come as a big blow. It takes so much energy to do this parenting stuff and when one child has some issues (for lack of a better word) as I know with my William it takes even more energy. So for lack of a better word I am sorry and my thoughts are with you. Hopefully you will be able to relax and enjoy your vacation with the kids.

I replied to her:

I didn't write to you about Edward cause it was pretty hard and I didn't know how to explain it. Edward did what he wanted to do - he got himself expelled because he wanted to come home. I just feel that he is doing what is right for him and he is carrying the consequences. It was also an angry reaction to John. I'll write more about it some time when I have taken some distance. Jean-Luc has been absolutely great, but it exhausted him too! It happened just as I was going to England for my revision weekend for my exam which I took on October 11 and I didn't stop working and studying before. Like you when things are

stressful and there is lots to do I become cold and efficient, and focus on what needs to be done. Right now I could do with a week on my own just catching up and listening to my inner self.

I wrote to my sister on November 7, 2001:

Edward is ok. He is getting some knocks at this school where he is – the social-economic-cultural level of his schoolmates is very different. He gets bullied by a girl. But this is what he wanted to do; go to a school where there was little school work and few expectations, and live at home. He is bored, he misses his friends and the sport at the boarding school. But he likes being back at home. He has been so much "helped and assisted" in the past few years that this is all a bit of a shock to him. Even to the extent where he expects his breakfast to be ready for him when he gets up so he has a lot of learning to do. I am worried that he will get depressed, but then again depression is a natural process which helps people to change their attitude. Jean-Luc keeps tabs on him by talking to the school. We have a hunch that he will get so bored that he will be ready to be challenged by main-stream school soon.

Following the consultation with Dr. H., I talked to Dr. M. about Edward and Beatrix's late physical development. A few years earlier she had taken x-rays of their wrists and hands, and told me that they were about two years behind their age group in their physical development. She told me to take them to see Dr. S., a pediatric endocrinologist at a private hospital outside Geneva.

My memory is of one visit, but the family calendar says that there were two consultations. On December 7, I took the two children. I stayed in the room with Beatrix while he examined her first. He was an older man, perhaps an elderly man. He was short, very white haired and had the kind of crinkly skin of elderly people. He was working most probably on a part-time basis. He was very courteous. He was very respectful of Beatrix. He told her that she seemed to be in good health and there was no reason to worry. He then called Edward in and I left the consulting room. He examined Edward.

According to the family calendar, I returned on December 21 with Edward. He said it would be necessary to do a blood test to confirm his diagnosis. He was, he said, 99% sure that Edward had a syndrome called I couldn't retain the name. He repeated it for me. I took out a piece of paper and wrote it down, "Klinefelter". He corrected me, it was "Klinefelter," and it wasn't that terrible,

it only meant that Edward would be sterile. He said we would have the results in a month, and we scheduled an appointment for January 18.

We left the clinic, got into the car and started driving home. Edward said to me, "Don't look so sad, Mum, it's my body, not your's". I was thinking about the signification of what we had just heard, what did it mean for Edward's life. Would he have a normal span of life? Were there other medical implications that we didn't know about? I could hardly remember the name, let alone anything else he said. We had to stop off at the Balxert Mall to go to the Swisscom shop. I called the pediatrician and told her that we had just come from Dr. S.'s and gave her the diagnosis. She said to me she would call me back. While we were at the mall, she called back. She said that it was not her fault that she had not diagnosed this. I don't remember what else she said, but it seemed clear to me that she was not worried about what this diagnosis would do to Edward and me, she was worried that she would be blamed, she was worried about herself. I said to her something along the lines that I was not calling to ask about her, I was calling to tell her about Edward. She was saying that it was such a rare illness, that she hadn't thought about it. I said to her, I am not blaming you. I just want to talk about Edward. And on she went. Eventually I told her that I didn't want to talk to her anymore. This is perhaps what she was expecting, but it wasn't because I blamed her. Weeks later, I got an invoice for that telephone call for 27.- Swiss francs. I remember debating whether I should pay it, and thought that if I didn't pay I would be keeping the relationship open. I paid it.

Charlotte wrote to me on December 25, 2000:

I just wanted to say I am truly sorry to hear about Edward. I can't get it out of my mind; I feel such pain for you and he. I can't imagine how you are coping. So my thoughts and "prayers" are with you this holiday time. I hope you get some rest and recharging to go back home and deal with this. I wish we as a family were closer because in a time of need like this you need to have us around you, emotionally and physically. I guess we all find family where we can and I feel sure that is what Jean-Luc is for you. Lucky you.

2001, the year Edward's identity was questioned

Entry in my diary on January 3, 2001:

I've taken this diary to Los Angeles and back. Haven't written down any of my dreams. This is the year we face Edward's illness. Thank God for a wonderful

holiday with Jean-Luc. I feel strengthened. What do I need to focus on? I-Ching 52, line 6: Noble-hearted keeping still. Good fortune.

My letter to my sister, Charlotte, on January 5, 2001, on my return from vacation in the US:

We had a great time touring around south California and Arizona. We did 1791 miles! We saw the desert, the Grand Canyon, Monument Valley, Lake Powell, Las Vegas and a little bit of LA (Hollywood). Apart from a little bit of jet lag I'm doing ok. I do feel that I have got my energy back and am feeling stronger.

Jean-Luc printed out a mass of information on Klinefelters which he read during our vacation. Every once in a while he would give me some of it. It seems incredible that no-one in our medical world ever thought of this as it is quite common; two in every 1000 males. All kinds of things could have been picked up on. We consulted so many people, and the "signs" could have been picked up by the paediatrician, the orthodontist (Edward has teeth which have no roots) the paediatric urologist, the neuro-paediatrician (I am not sure of the right words in English).

Jean-Luc contacted a friend yesterday from London Heathrow who knows one of the best genetic doctors who could help if need be. Our next appointment with the endocrinologist is on January 17. I think Edward's psycho-analyst will attend with us as the doctor wants her in on this. He has already spoken with her. She is a wonderful person. Which means that we are already starting to form a support group for Edward which is the most important thing. I think we will need to understand better what it means for him and what he needs as support. Hormone replacement therapy seems to be on the cards - it comes in all kinds of forms but Jean-Luc thinks that implants will be the best solution for Edward, rather than under-the-skin daily injections (like for diabetics). So right now it is wait and see which is the hardest part I guess with any medical problem. I am going to read the book Jean-Luc printed out today and try to spend some time with my feelings before Edward and Bea come home from camp tomorrow. And I am looking forward to seeing my analyst on Monday!

You know what it is like to have a child who is considered different and difficult by others so you do know how one copes. You protect your child as much as you can, I have been told too that I have been over-protective. I think the hardest has been dealing with other people's emotions around Edward, people who

have inferred that his problem is due to lack of good parenting. And I know that I too can be judgmental of parents with difficult children so it is normal, but I get so fed-up with people telling me that Edward needs this or that, and off-loading on to me because they cannot deal with their feelings. For example, my neighbors (Sylvie and René and their daughter Julie) who have become quite good friends over the past six years regularly off-load. René thinks that Edward is missing a male role model and that he feels that Edward is "asking" him to play that role, but that Jean-Luc should be doing more of it. The same man hits his daughter and pulls her hair. When I explained before Christmas to Bea that her brother has a genetic illness and that he will get better (and discussed with her what better could be for her), she burst into tears and told me that Julie has told her that Edward's problem is Beatrix, that she is too smart for him and has always put him down - because that is what her parents have told her. However in spite of that, Sylvie and René have been great with him, he goes upstairs and plays on the Playstation they have and watches movies with René, talks to Sylvie. I made up my mind years ago that I would only listen to those people who actually spend time with him - and I told my sister-in-law, Annie-Laure, and her husband Dennis that. And they do look after him and Bea every once in a while. I have to admit that since Edward has stopped going to boarding school I really do not miss the constant criticisms of the teachers over the phone. When people tell me I am over-protective, I think that those people have a personal problem with the fact that I love my child so much and do so much for him that they are envious because they never got that kind of love and support from their mothers or fathers.

I don't think there is a right way or one way of parenting. I beat myself up for all those years when I was not available for my children during the day, working my butt off to pay for a house and my husband's studies. When young working women ask me about being a working mother, I tell them to get Brazelton's book about working mothers and to read it.

I tell them that you never know what will happen, but one parent has to be available all the time. I am so happy that Edward has come back from boarding school, I really like having him home and I am so glad that we will be dealing with this with him at home. I am so much more available and have been since I went "free-lance".

I guess I have a certain amount of angry feelings with the doctors who missed the signs, with all those who have criticized him. I formulate letters in my head to the doctors. I am thinking of writing to the head-master at the boarding school. I want those people who criticized him to apologize to him. But on the other hand, just because you know someone has an illness or a handicap doesn't make living with him or her easier, and people are only human. Jean-Luc says that according to the medical information, nothing medical could have been done until he was 13 so we are 3 years behind (some men are not diagnosed until they are adults and want to have children!), but we could have had the schooling assistance and the psychological assistance that was appropriate. I will apparently be able to claim back from the social insurance all his private psychotherapy and dental/orthodontic treatment, maybe even his two years of private schooling, and that can go to providing him with appropriate help.

On the other hand, looking at things positively, we will have a diagnosis which will bring help to Edward, medication that will help his physical and psychological development. You know as well as I do, that when he is better I will be better too because I think I have suffered most from having a child who suffers. Having an unhappy child, a child who doesn't fit in socially, who suffers from lack of self-esteem, who can't make it academically although he is bright and imaginative, who is aggressive but can be charming and lovable at times, is the hardest. It has also been hard over the past year because he has been asking questions about his future. He asks, "What happens to ADHD kids when they grow up?" and now he will ask, "What happens to Klinefelter Syndrome (or XXY) men when they grow up?" What the diagnosis and medication will do, is help him to grow up physically and mentally and psychologically, because until now that is what has been impeded.

I will most probably have to be tested too to see if I was the one who passed this on to Edward. If I had done an amniocentesis we would have found out before his birth, not that that would have changed my mind about having him. I will let the family know when I have had this because we all have to know whether this is something that is in our family genes. I guess the endocrinologist will tell me what the chances are and who needs to be tested. When we have seen the endocrinologist and get the diagnosis (Klinefelter or XXY or whatever) and know which route we will take and what we will tell Edward, then I guess I will write a long letter to everyone (i.e. Matt, Mark, Dad and Mum and you - but it may be repetitive) and explain.

I am going to print out a copy of this for myself, and go home and have a good cry. I guess I need to get my grief out of Edward's way. Thank you for your support. It means a lot to me.

Charlotte's same-day response:

I realized yesterday that you must have come and gone and we never spoke! But it sounds like you did exactly what you needed to do, process some of this about Edward and get relaxed. You will need all your energy and emotional/psychological resources to get through this and being well rested is a start. I can imagine your anger at the doctors and of course at all those stupid people with ridiculous advice. For those people I try to let it go in one ear and out the other, but for the doctors it is harder to let it go. It seems to me what often happens here in the States is out of this comes someone who forms a support group or gets involved in support groups and begins to educate the public. In the meantime I wish you luck getting through the next few weeks. You have a lot on your plate and it is great to have Jean Luc but you also need John to help you and I am guessing he is not available.

And as you saw Beatrix needs you too. She has been living her place in the family and it must sometimes be a difficult place to be. When one child is in so much pain you as the other child cannot have any pain. It is tough and I don't envy you at all. I think you are so lucky to have Jean Luc to take you away to restore you and keep you informed with all the medical info you need. You have a lot to grieve about and I am not sure you'll get it all done in one good cry. So I am thinking of you and stay in touch.

On January 10, 2011, I wrote to Edward's father, John:

I have some more reading material which I am plowing through right now. I am also highlighting the important bits for future reference. We get the diagnosis on Thursday next week - so nothing to do until then. Dr. S. has already been in touch with Berthe to form the support group. He will want to have a meeting with the support group soon so that we get "our attitude" right. I talked 5 minutes with Edward the other day about it and he says he wants the doctor to explain it to him. I have total confidence in this doctor. (I am quite mad at all the other doctors who never saw the signs.) It is likely that Edward will have to take hormone replacement therapy all his life and it is best given "under the skin" in the form of daily injections or as an implant. I think the second option will be best. He will then "develop" into a teenager.

I think we have to decide right now that as far as schooling is concerned we don't decide anything. Jean-Luc says glibly that he can go back to Maya Joie in September, but I think that Edward doesn't want to go back to a place where he was criticized for not making an effort, when he was not capable of doing so. And I will continue to protect him against criticism - so I think that we may be looking at another academic establishment but it will be paid for by the Assurance Invalidité. This has to be considered as well - he will get more support from the state. AI recommended a different set of schools. So that is something we can look at in the springtime. He has said that he misses Maya Joie for the friends and sports, not for the school. He has turned down my offer of finding another school in Geneva. I am still not yet ready to consider sending him away - not until he grows up. Edward is a little boy.

I am so sad that he is ill - as sad as I was when I found out that Eva was ill, that she was dying. I cry when he and Bea are not around. I don't want him to be ill. But I am glad that we have finally found out what it is and that real help (medication, etc.) can be given (although I am not sure that I really believe after all the disappointments we have had).

The information that Jean-Luc downloaded from the internet and printed out in December 2000 included:

Hambley, V. 2000 *What is XXY?* retrieved from
 wysiwyg://XXYMAIN.294/http://47xxy.org/
 XXY.html on December 21, 2000 at 15:19

Abramsky, L. & Chapple, J. 47,XXY (*Klinefelter syndrome*) and 47,XYY:
Estimated rates of and indication for postnatal diagnosis with implications for prenatal counseling

Bender, B.G., Linden, M.G. & Robinson, A. Neuropsychological impairment in 42 adolescents with sex chromosome abnormalities in *American Journal of Medical Genetic* (Neuropsychiatric Genetics) 48:169-173 (1993)

Bender, B.G., Harmon, R.J., Linden, M.G., Bucher-Bartelson, B. & Robinson, 1999 Psychosocial competence of unselected young adults with sex chromosome abnormalities in *American Journal of Medical Genetic* (Neuropsychiatric Genetics) 88:200-206 (1999)

Klinefelter, H.F. Klinefelter's syndrome: Historical background and development in *Southern Medical Journal*, Vol. 79, No. 9 (September 1986)

Klinefelter's syndrome, pages 1316-7, *The Lancet*, June 11, 1988

Linden, M.G., Bender, B.G. & Robinson, A. Intrauterine diagnosis of sex chromosome aneuploidy in *Obstet Gynecol* 1996;87:468-75

Nielsen, J. & Pelsen, B. Follow-up 20 years later of 34 Klinefelter males with karyotype 47,XXY and 16 hypogonadal males with karyotype 46,XY in *Hum Genet* (1987) 77:188-192

Paulsen, C.A. & Plymate, S. R. Klinefelter Syndrome, in *The Genetic Basis of Common Diseases*, 1992, 1st edition, edited by King, R.A., Oxford University Press Chapter 44 pp. 876-894

It was Hambley's online article *What is XXY?* which became my preferred document. It is 5 pages long, and written in a non-academic, non-medical style for people or parents of people diagnosed with Klinefelter. Dr. S. said to me that the most serious effect of Klinefelter syndrome was that Edward would be sterile. He later told us that we should not tell Edward that he was sterile because it would affect his sexual performance. Looking at the first page of the document it states that the features of those with this genetic condition are:

- *Tall (around six feet)*
- *Small testes or hypogonadism*
- *Inability to produce sperm*
- *Sparse facial and body hair*
- *Gynecomastia*

On the same page, it states

Subsequent research studies expanded and revised the original features to include the following as possible associated conditions:

- *Infertility*
- *Incomplete masculinization; feminine, or pear shaped, body and body hair distribution*
- *Decreased libido*
- *Osteoporosis*
- *Taurodontism*
- *Venous disease*
- *Learning, emotional, and mental disorders*
- *Autoimmune disorders such as lupus*
- *Low energy*
- *Low self esteem*
- *Communication difficulties, especially with expressive language*

- *Frustration-based outbursts*
- *Motor skill issues*
- *Developmental delays*

I can remember reading the other articles, but not retaining any information. What I was missing was someone who could make sense of the information in relation to Edward.

So when I remembered that I had a copy of Gross's chapter in early 2001, I re-read it, and this is the paragraph under the heading of "Hermaphroditism" that caught my attention:

This term is currently used to refer to any discrepancy or contradiction between any of the various components of sexual anatomy and physiology, although, strictly the term hermaphrodite (from the mythical Greek god/goddess, who had attributes of both sexes) denotes a person who has functioning organs of both sexes (either simultaneously or sequentially). So included under this heading are:

- 1) Chromosome abnormalities, where there is a discrepancy between chromosomal sex and external appearance, including the genitalia (the best known are Turner's syndrome (XO) and Klinefelter's syndrome (XXY).*
- 2) Testosterone insensitivity or testicular feminizing syndrome.*
- 3) Adrenogenital syndrome.*
- 4) True hermaphroditism (the others are, strictly, pseudo-hermaphrodites).*

So my son has a chromosome abnormality.

Entry in the family calendar on January 11, 2001:

Jean-Luc goes to the Cayman Islands for Laurent's birthday

Letter from the Cantonal Office of Disability Insurance, signed by Ms. S., psychologist, dated January 12, 2001, translated from French:

Following our meeting last summer, we are writing to you to keep informed of Edward's current situation, and to arrange, if necessary, a meeting to discuss more in depth. We therefore propose that you contact us at the following telephone number (except Mondays).

Entry in my diary on January 29, 2001:

I don't want to write out what I think is happening. It's got to such a point that even the children say I yell at Jean-Luc all the time. But he admits to being in a bad mood and says we always argue. I'm more demanding and he can't take it.

Letter to my sister, Charlotte on January 29, 2001:

Edward's illness was confirmed on Jan. 18th and he has decided that he will start the treatment in February. He will have an injection "in the hiney" once a month. He is very fragile, hence so we all are. But we are hanging in, dealing with the moments as they come up, but I am afraid that he will have an accident as that is his normal response to being confused and unhappy. So fingers crossed.

I don't think I will write to everyone about it. I called M&D last weekend before they went off to Europe and talked to Mum who sounded quite strained. She told me Daddy wanted to talk to me and he came on the line, asking for forgiveness because he told Matt & Sue over the Christmas vacation.

We have decided not to tell Edward about the sterility issue because the research shows that the HRT improves sperm production, and we do not want him to mix up sexual activity and reproduction. However he only has to go onto the website and see some short version of the description of the illness which includes that - or some one else can and then inform him. So right now I am not reminding/telling anyone of the name of the illness.

I am pretty emotional right now. I have loads of official papers to fill out and have to write down all the doctors who saw Edward. I am overwhelmed. We should be able to work out a strategy which protects Edward. In any case Edward has said that he does not want anyone to know.

Oh, Charlotte, thank you for writing. I hope your kids get better and that the au pair comes back. Murdering your kids symbolically once a month is normal. Husbands at least once a week! Hope life gets better for both of us.

Entry in my diary on February 2, 2001:

Edward is not doing well. Jean-Luc and John think he should move ahead quickly – if you have a headache, you take an aspirin. Berthe says, "Madame

Lindley, you are asking a little boy to make an adult decision.” What is right for Edward?

What is going on with Jean-Luc? He is not doing ok. When I am needy he runs away. I have said what I don't like. And he claims he needs space and goes out drinking.

Handwritten letter from Edward to Dr. S., dated February 12, 2001, translated from French:

Dear Dr. S., I agree to doing your therapy. Best regards, Edward

An extract from Charlotte's e-mail on February 17, 2001:

Having said that how is Edward doing? I hope you are coping. I just found the copy of your email and I understand completely that he doesn't want anyone to know. He has been judged by all of us in the family re his behavior so it is not safe. I hope for all of us that will change, i.e. being safe.

E-mail to Charlotte, dated February 19, 2001:

Edward had a terrible weekend with his stepmother and father. We had a long talk last night after everyone else had gone to bed. He asked me if he could start his treatment, cause "life just can't get any worse". And luckily he had asked for an extra session with his psychotherapist today. I had a session with her and Jean-Luc two weeks ago which was very good for Jean-Luc and I because we have been doing what normal parents do, we were trying to make the other do what we didn't want to do, so we got our fears and perspectives out.

It must sound all pretty grim, but there is a good deal of hope. Edward and I have some "five minute windows" where we really connect. No matter how difficult my children can be sometimes, I really like these young people.

Ayayaayaa! what it is to be a mother and a wife and a woman. It is so counter to the social image of external success. We are the glue that makes a family work and stick together. That it is the little things we do everyday, like go out in the storm to pick our children up from school that count. I read somewhere; love is not a noun, like a name for an attitude. It is a verb. That's why I guess we should also give our partners the opportunity to do things for the kids.

Entry in my diary on March 28, 2001:

Worried about Edward. It seems like his need requires a strong man, and I'm being terribly female, at odds with my masculine side. There's a battle inside my psyche. Doesn't seem like I've found a competent animus. A time for female strengthening, says Evy, "not paranoid, just full of doubts".

Entry in my diary on April 12, 2001:

Leave for Cayman. Edward has gone to stay with Annie-Laure until Easter Monday, then he goes to his fathers.

Entry in my diary on April 27, 2001:

Miserable, tired. Edward had an accident last night and I showed him and doctors that I was not happy.

E-mail from Charlotte, dated May 5, 2001:

I went to a lecture a couple of weeks ago by a man called Richard Levoie. He has a couple of videos one called "How Difficult can this Be". He runs a school for Learning Difficulties in Mass. He was amazing and inspirational. I thought of you and me and why it is so difficult with these kids. One thing he said is that we don't get a diagnosis until usually kindergarten or 1st, 2nd grade and suddenly all our hopes and aspirations change and we go through different stages of denial to eventual acceptance. As far as Edward is concerned you probably were at acceptance and are now back at the beginning of denial and going through the stages to get to acceptance again. It is tough. I am glad you have a good therapist for Edward to help you all deal with this.

I received a registered letter from the Geneva Public Transportation dated May 21, 2001.

The subject given was: Abusive behavior

We inform you that your son, Edward, was found travelling on the "cloche" (the part that hooks two carriages together) of the tram on Friday afternoon of May 18th. Caught by our agent, your son followed his instructions correctly, which allowed us to talk to him in our offices and to make him aware of the dangers he was exposing himself to. We hope that we have convinced him, in his own interest, not to do this again, and are sending you his season ticket attached to this letter.

E-mail to John, dated June 1, 2001:

Edward did not go to his "stage" (a trial internship before choosing an apprenticeship) in the end and skipped school on Wednesday / Thursday. His skates were repaired on Monday because he had been working well at school and hadn't been skipping school; now they are confiscated again for a week.

Response from John, dated June 6, 2001:

He was also spotted by Judith hanging on the end of a tram and enticing other kids to do the same, I talked to him about this last week-end (but did not reveal the origin). The only thing I wonder is how effective all this is, he just adapts and accepts things. In any case he also told me that he had decided/accepted to do an extra year (well done).

E-mail to my father, dated June 1, 2001. Beatrix had been away for a week on a school trip to Barcelona:

Spent more time with Edward who is very indecisive and hence stressed about doing an apprenticeship. And of course I cannot say anything right... Still packed him off to see his therapist this morning with the hope that maybe she can make him articulate his thoughts and feelings.

E-mail to John, dated June 11, 2001:

In our trials and tribulations with Edward, I was really horrified on Tuesday evening to find out (while stuck in a grotty hotel in Reading) that the police had come by to the house because Edward was being chased by some friends (!) and had taken out his air pistol to go and shoot them. I don't know who called the police, but the police came around and showed Edward their guns and compared them to his air pistol. They told him that if they saw him on the street with the air pistol they would not be able to differentiate between it and their type of gun. Apparently Edward was quite shocked, because they added that they would shoot first and ask questions later. They took his air pistol away and Jean-Luc asked them to keep it. He also asked them to take Edward down to the police station and keep him in a cell overnight, to teach him a lesson, but they said they couldn't do that. I feel betrayed. I have always said that what Edward does with an air pistol happens at Peney, and that under no circumstances should an air pistol or any form of arm come into my house. You worry about Edward smoking hash because you say it leads to heroine. What does an air pistol lead to? A machine gun? Killing your classmates?

Still Jean-Luc was in charge last week and he did a fine job handling the situation. Please do not ever buy Edward an air pistol or any form of arm again.

Edward has to go and see the doyen (principal) to see if he will be accepted at the school for another year.

One of his friends towed behind the tram sometime ago and had his face smashed and bit his tongue off. I hope that will put a stop to that. His skates are indefinitely confiscated.

Trying to survive the trials and tribulations of having a delinquent son, Kate

John's same-day response:

The gun is another problem; I had confiscated it from him last year because of an inappropriate use. He must have found it and taken it to Geneva. Sincerely I agree with you he is not to be given this kind of thing and I will not allow it either. Previously my thinking was that it was a way of letting of some steam in controlled circumstances but given the context (his state, friends and general atmosphere) I think I was wrong.

There was also another money incident this week-end, he took CHF 30 from Bea, but admitted it and said he will return it on his weekly money.

In the summer vacation, I took Edward and Beatrix to stay with our neighbors, Julie and her father, René, in Sicily for a week. We then went to the south coast to the Club Med and had a week there. During the week, Edward made friends with an English boy who wore dresses and painted his nails. Beatrix said that she was upset by the way Edward was talking to this group of young people. She found another group of friends. After the week at Club Med, we went back to Julie's and I left Bea there for another week or two of vacation. I flew home with Edward on July 27th.

On one of the following days, we went for drinks with Sylvie, Julie's mother, who was in Geneva. Edward stole 200 francs from Julie. I can't remember how we found out, but we paid Sylvie back immediately.

Entry in my diary on July 29, 2001:

Back from 2 weeks vacation in Sicily and Edward has gone off and is not back at 22:30. I can't hold this kid. He has no self discipline, no restraint.

I called the social assistant, Mrs. S., because I did not know what to do with Edward. She gave us an appointment the same day. She talked to Edward separately, and afterwards she told me that we were taking him to hospital. She took us in her car.

When we got to the hospital, she talked to the nurses at the emergency psychiatric admission. We were shown to a small consulting room. While we were waiting there, Edward got fed up waiting and went outside to have a cigarette. He then started picking up the garbage cans, detaching them from the lampposts, and hurling them on the ground. Mrs. S. and I stood by the window watching. She said to me, "You are not reacting. You have got so used to his aggressive behavior you think it is banal." We watched as the security guards came out and stopped Edward from continuing. They brought him back to the room.

E-mail to my sister Charlotte on August 1st, 2001:

Edward is clinically depressed according to the doctors. And that is about all I know. Today is a holiday (August 1st - Swiss National Day) so there are no doctors on duty in the Crisis Unit, just nurses. I stopped by today with Edward's music box and CDs. I saw him for a moment, but normally I am not allowed to visit until 48 hours are over. The nurse said that he had slept well. He asked me if I could bring his skates over, cause he is allowed to be out 2x 2hours a day accompanied by a nurse. The nurse interrupted him and said that the contract was that while they were taking care of him he is not allowed to put himself at risk, so no skates.

Daddy also mentioned that I should tell the doctors of the fact that there is manic depression in the family.

I don't know whether they have put him on tranquilizers. He seemed very calm today. I don't have access to the clinical definition of depression, but I do know that there are quite a lot of symptoms (trouble sleeping, trouble remembering, etc.). It could be that he took speed on Sunday, but Edward in the past has turned on both Beatrix and Judith (John's wife) with a knife. He has also said when really angry that he wanted to kill himself. I talked to a psychiatrist for

about 45 minutes on the phone, a Swedish guy from the Crisis unit who deals with prevention, and he said that the fact that Edward had had so many accidents (over 26 trips to the emergency ward) that he has a pattern of self-destructive behavior. So I hope that with the intense psychotherapy, the constant presence of a psychiatric nurse and the framework, plus possibly tranquilizers, that he will be able to express all his fears and move forward. Yesterday when we walked from the emergency psychiatric ward to the unit, he seemed relieved that he was being taken into care. The nurses are very respectful towards him. When I left yesterday they said that I would be asked to join his therapy sessions - or to have some family therapy sessions, which sounds good. After I sent you the e-mail yesterday, I realized I hadn't told John ... so I called him.

Letter to my family on August 3, 2001

I just wanted to say that I went to see Edward officially this morning and had a session with the psychiatrist, nurse, him and me. He is doing ok, calm (but no medication) and non-aggressive, but still depressed, so sad at moments. The team there insists that he is going through an adolescence crisis, which is aggravated by or the sum of different factors, but there is not one that is determinant. He seems to be content being there, and is allowed to go out for two hours each afternoon with his friends (if they come to pick him up and bring him back). He has informed a lot of his friends that he is there - and has no time for me to visit him in the afternoon, which is ok. The team is also giving me a lot of support, which is great because "my analyst is out of town". We seem to agree that Edward has made a big step forward in accepting that he is depressed and needs help, and taking it. He also is relieved that his distress is being taken seriously.

Entry in my diary on August 5, 2001:

Edward was hospitalized on Monday, July 30, on a voluntary basis. What will change? How will I cope? What will I have to do differently?

Entry in my diary on August 6, 2001:

There is a lot of feeling lurking about underneath the relief. I know it's there, but I don't know what it is. It would be great to do a co-counselling session. "Il y a urgence chez Edward!" Yes, but for pleasure, for "I want to do this", for the childish activities. (Tears) Fears that he won't grow up. Would like some

reassurance. Would like to see some sparkle of hope that he will be all right. I'm scared for his future. I don't understand my role.

Extract from my e-mail to my friend, Richard, on August 6, 2001:

Edward was hospitalised on a voluntary basis yesterday in an adolescents crisis unit suffering from severe depression. The unit is pretty neat, it's in a duplex apartment, no locked doors, no uniformed staff, individual bedrooms and very respectful, friendly atmosphere. We are both relieved. I can visit as of tomorrow every afternoon - if he invites me.

Richard's reply on the same day:

Keep me informed. And if you wanted my - relatively informed - views on antidepressant medication feel free to ask. Do note that ca 1 in 20 of folk put onto SSRI (i.e. Prozac and that ilk) 'overreact' dramatically and have violent thoughts (and occasionally actions) against themselves and others. But the unit does sound a couple of orders of magnitude better than many, so they should be keeping a good eye on him.

E-mail to Richard on August 6, 2001:

Oh, gee, I wish we lived in the same area, then we could get together for chats. About above, I know from Edward's psychotherapist that the hospital psychiatrists did a presentation on psychiatric medication and said that it was counter-indicated for adolescents. They gave him a tranquilizer to help him sleep on his first night because he was very upset and they offered it and he accepted. But it did knock him out at 10:00 pm cause when I went in at 9:30 am he was still asleep. He has not had any since then.

Would love to have a co-counseling session, but am doing some discharge on my own. I woke up very confused, and started talking it through to myself which started the tears flowing. Then I was listened to for 20 minutes this morning over the phone by a nurse in the unit which was helpful. What is good is that they are so used to adolescents. They tell me that Edward is going through adolescence and that is always difficult, but they do agree that it is particularly difficult for him because he does have Klinefelter's syndrome. Anyway, have got some clarity: I am angry with him that he has not been able to take advantage of what has been offered to him, and I am scared stiff that he won't want to take advantage of anything I can give him. I just feel we could work like a team together. So I guess I have some grieving to do about the past, which will

hopefully free the way forward without either totally letting go, but using my energy appropriately.

The main points I remember from Child Psychology are what Winnicott said about "good fit" between parent and child, sometimes it happens and sometimes it doesn't, and the statistics on the number of arguments between parents (themselves) and between parents and teenagers (roughly the same!, i.e. between 2 and 3 per week). We are statistically normal! So be damned (put politely) ideological norms about happy families!!!!!!

My sister-in-law, Sue, responded on August 7, 2001:

Thanks for keeping us informed of what's happening with Edward. Things must be pretty difficult for you all right now and as usual we in Congleton feel for you and think of you often. It must be a good thing that Edward has recognised there is a problem that he needs to have help with and hopefully the support he is getting will also help relieve some of the "burden" on you.

E-mail to my sister-in-law, Sue, in response to her e-mail on August 7, 2011:
Hey what good mother does not feel guilty at least some of the time, that is if she cannot manage feeling guilty all the time (she usually has to be Jewish or Catholic for that!). It seems to be a natural part of motherhood, but you do get a variety (spice of life?) of different things at different times - until they start blaming you ... then you can rely on them and you stop being your own worst judge. Being a mother seems to me to be the "best contribution" you can make to life. I have said in the past when I get to the Pearly Gates I would like to be able to say I have been a good mother, rather than a good trainer or manager or whatever. (Maybe I won't get to the Pearly Gates. Maybe they don't exist. And all that hard slog and effort for nothing....) I have also been known to say that I am not only a mother in fits of pique, so ambivalent all round.

Edward asked me to go over and keep him company yesterday (there was no one else available - truth!) and we went out for a bit. No tantrums, no swear words. The nurse told me he is very sad and depressed about being different. They are organizing a day center for him to go to when he leaves there which would be latest end of August. From the moment that he and the doctor decide that he will leave and actually leaving, there is about a six-day gap. He is quite content to be there, but for the first time today he said he would like to come home and go to circus school next week. But that is not really a possibility. His

psychotherapist is back from vacation and he sees her on Thursday. She is very much in the loop now.

What amazes me is how the doors are opening one after another and how much help there is. I called the day center in April, and they didn't want to know.

What is different this time is that he asked for help, whereas in the past I asked for help. Jean-Luc is amazed at the fact that I owned up that I couldn't cope anymore and made it clear to Edward. He is also amazed that I am not feeling guilty. (Maybe I have outgrown it?!) But there is a lot of sadness and frustration that we are here and that we didn't seem to be able to avoid it. The team at the crisis unit tell me that I bear 'minimal responsibility', a part of the responsibility is mine. They really are very supportive. I can call and talk (and cry) on the phone with them at any time.

Charlotte's e-mail on August 9, 2001:

Dear Kate sorry so long in replying! When I went to that lecture by Dr. Rick Levoie he talked about how the continual cycle of failure in school makes kids really depressed and terrible low self esteem. I hear you are in Reading but assume you get your emails. You are amazing at sending all those emails with updates, because we are all concerned and are glad to at least be some support. There are some amazing drugs for depression out there.

Extract from John's e-mail of August 14, 2001:

I am thinking of E a lot, poor kid, I hate seeing him behind bars but I can really understand your problem coping with the situation as I have the same difficulty.

My same-day response to John:

I guess it's a question of perception. If the doors have opened for Edward to receive professional help, it's because he needed it and asked for it. He spent that first day at the hospital with me, Madame S. and the staff saying no, he wasn't coming with us while walking towards us. I think he has made an incredibly big step forward. He is starting to come to terms with himself and his illness and he has the space to be sad while being protected and cared for. I don't have a problem with him being where he is, I am incredibly saddened to realize how sad he is. He is taking steps towards assuming responsibility for himself.

He came home yesterday evening for Bea's party and when it was time to go back he reminded me it was time to go. He accepts the rules, which is good.

Entry in my diary on August 14, 2001:

Edward's coming out on Friday. I don't know if I can cope. The day center isn't fixed for a definite date, the school SGIPA hasn't sent the forms, the Assurance Invalidité (Invalidity Benefits) hasn't go their act together. I just feel so weak.

Entry in my diary on August 15, 2001:

Breakdown. Edward ran away to Maud's.

Entry in my diary on August 16, 2001:

Edward back at UCA.

Entry in my diary on August 17, 2001:

Meeting on week-end at UCA. Sick all weekend.

Letter to my family on August 20, 2001:

Edward didn't come out last Friday because I had a breakdown. Now that the health authorities have got the message that I didn't just need a break, but want professional help for Edward to relieve me, they are having to rethink their strategy (which was formerly "just send him back to his mother, she is strong and she will cope") and will have to put in place the structure quicker than they wanted to. For the story, they told me on Tuesday (August 14th) that the day center would not be available for a long time, but Edward would have to go home because the unit's doctor was going on holiday, and if I had to stop everything else, such as work, so be it... So now armed with some mind-

numbing and anti-depressive drugs from my doctor, and loads of advice, I have to go back and struggle to obtain more professional help. I find this all very humiliating; I have to break down for them to start listening but as my doctor says the health authorities are used to handling with crises so they can deal with mine too.

Edward is doing ok. He really appreciates the care he is receiving and feels comfortable at the unit, although bored. He told me that he understands that I can't cope on my own and that he has to wait a while before he can come out, anyway the deadline is August 31.

We had a session (Jean-Luc and I - yes he is still around) with Edward's pyschoanalyst-therapist last week and she said that I had to change my attitude towards helping Edward. She said that from now on I have to do the right things for Edward not in the hope of "curing" him, but just because certain things have to be done. I have to stop hoping that he will get better. She said then I will stop being disappointed, and that in the long term things most probably will get better, but not the way I intended them to. So for a control-freak who thought I'd cooled it, I still have to learn to "let go". My doctor said I had the mind of an Excel spreadsheet. Can't think of a "smart" way to end this message.

Same-day response from my brother, Matthew:

Very sorry to read your latest news. It is difficult to really appreciate just how hard it must be for you all. Your last paragraph makes me think of mine and Mum's situation - we don't really get better rather we have to live with it. It had not occurred to me that that would be the same for you and Edward! So your doctor thinks you're like a grid of boxes and we put bits of you in any of them? or is it that you are so adaptable and multi-functional!!! It's just a question of finding the right function and the parameters to go with it but you have to be wary of CICO(Crap In, Crap Out). Take care and thinking of you.

My response to Matthew on the same day:

Thanks for the support. I hadn't thought of you and Mum, but thank you for telling me that about you. It's true that I have sometimes stopped to think that you have had to come to terms with what you had/have and didn't have, and that I admire you enormously for having made your way.

No, my mind is like a spreadsheet. I am the one who manipulates the little boxes!!!! I am the control freak. I am the one who does the cut and paste here! Adaptable and multi-functional, thank you! What I didn't say is that I have never been able to use Excel properly because I am not a mathematician! Just a calculator. We should develop a personality test for IS gurus? Are you a word document, a spreadsheet or a Lotus Notes? We could make millions.

I have just spent 45 minutes on the phone to Edward's psychotherapist who tells me I have to separate my feelings. Anger against the doctors, and sadness / caring for my son - and not to get them mixed up! I am not getting much work done, plus my Word document keeps on blocking every time I try to apply bullets. Don't read anything psychological in to that - I am not trying to shoot bullets! Thanks for making me laugh.

Entry in my diary on August 19, 2001:

Stiff all over.

Edward came home for supper. Told him we have to set up the centre du jour (the day center).

My responses (in italics) with Charlotte on August 21, 2011:

Hurrah for you, so what if you have to have a breakdown to get your needs met. I absolutely think you did the right thing.

Yeay! I am learning. Think I will continue to be the "fragile little woman" for a while!

What does Edward's doctor think about medicating him? Both Steve and I think it absurd that the hospital won't medicate a teenager. He is depressed (rageful, sad etc) and if the drugs help so what?

Right now he is in a space where it is ok to be rageful and sad. He needs to express them in a contained place. We had a session where he told me how he felt about me not taking him home last week. The therapist told him afterwards that he could do that without having to have a temper tantrum, and that I had listened and acknowledged his feelings calmly.

There are also medical reasons why (but I can't tell you the details) certain drugs used for depression are not right for teenagers, some actually do the

opposite. My friend, Richard Horobin, who is a bio-chemist applauds the hospital's decision.

It is a brain thing not a bad mother thing.

That we agree on. Maybe another thing that is being taken into account is that Edward has been given hormonal therapy, so his brain is already churned up and activating differently. My analyst said that it would be good to see if any research has been done on that. Edward had not started puberty when he was started on testosterone. I know that the psychiatric doctor at the unit has been doing his homework on Klinefelter, because he started sprouting all this stuff on Thursday, as if I didn't know. We have an appointment next Wednesday with the endocrinologist so I will find out more about how the brain reacts to having hormonal therapy before nature has started doing the work naturally.

Tomorrow I have an appointment with the social assistant and family therapist at the day centre. I've just come back from seeing my analyst. She is a good friend of the woman I'm seeing tomorrow and told me to tell her that I am in therapy with her. And now for an aspirin.

E-mail to Richard on August 21, 2001:

We are making progress. I have fallen apart and am being picked up and told that it is ok to fall apart by various supporting professionals and others who are giving me shoulders to lean on.

Just seen my therapist who questioned whether the fact that giving testosterone to a child who had not started puberty was not in itself a damage-inducing thing, and whether it had been researched.

E-mail from Richard on August 22, 2001:

Here is a quote from a review (Fisher and Fisher 1997) on psychoactive medication for children. Admittedly a critical review, but hey - -

"We found 13 double-blind, placebo-controlled studies that have evaluated the therapeutic power of antidepressants for children and adolescents [references followed] No one has really shown a therapeutic advantage for drug over placebo in samples of depressed children, with the possible exception of a few marginal instances. Actually two studies [references] have provide examples of placebo exceeding active drug in power."

But of course the physiological and psychological side effects are not related to

clinical efficacy, alas. This has been commented on in editorials. And at least one said that - since the psychiatrists surely couldn't be wrong, this was a case where the science didn't count. Yuck.

On August 22, 2001, Edward was taken from the UCA to the psychiatric hospital, Belle-Idée.

E-mail from John on August 22, 2001:

I imagine the turmoil and angst you are experiencing. As you must have felt, I felt devastated when I heard the news none the least because I have experienced this first hand. My heart filled with feelings of guilt, of sorrow and anger which I imagine you must have also felt. Nevertheless the nurse said that they had talked about how difficult this situation was and how they felt we, parents in the wide sense of the word, must have lived impossible times.

I had a conversation with the Doctor in "Les Glycines" and I must say that I was very reassured, he sounded much more professional than Dr. H.. He asked me what I thought and we were both probably comforted that we had come to the same conclusions. Dare I say that Jean-Luc had the same opinion when I met him at the trade fair in Lausanne (in other words why did we bother reading all this stuff in Psychology, in the end it is all just common sense you need). But we are parents and parents are parents.

I sincerely believe that for different reasons we have both come to a point of helplessness and that beyond the deep feeling of being inadequate etc. We will also live some accusations but such is life. We need to find strength in the feeling that we have just been "sufficiently good" and honestly tried albeit probably not in a perfect way.

My e-mail exchanges with John on August 23, 2001. John's responses are in capital letters, mine are in italics.

Yesterday I spent my morning with the social assistant at the SMP who is attached to the centre du jour pour ados. We were starting to look at the solutions, after I told her his history of scholastic failure.

I came out and called Edward who was in an ambulance. I went to the UCA at 15:00 to hear what had happened, and find out what would happen. The UCA people feel they have a part of responsibility because they did not deal well with

the anticipated "sortie" last week. In the sense, they tried to force me to take him home and I couldn't accept. They feel they abandoned him.

YES I GOT THAT FEEDBACK YESTERDAY PLUS THEY TOLD ME THAT THEY HAD ASKED THEMSELVES HOW WE HAD COPE FOR SO LONG.

Edward, according to them, has an incredible fear of being abandoned. So he tries constantly to find out how far he can push before he gets excluded. He told the staff at Glycine that that is why he has crises. And he said it worked at Maya Joie; they excluded him. And it worked with you too. I think Edward must fear being abandoning by me because you have portrayed our separation as being just that.

THIS IS NOT THE CASE. MY LINE HAS ALWAYS BEEN THAT THE SEPARATION WAS PAINFUL FOR ME BUT THAT YOU AND I HAD COME TO A POINT WHERE THIS WAS THE BETTER WAY TO CONTINUE. I HAVE ALWAYS ALSO INSISTED ON THE FACT THAT OUR SEPARATION DID AND DOES NOT CHANGE THE RELATIONSHIP AND LOVE WE BOTH HAVE FOR E AND B.

That is why I think it would be of mega-importance that you did some psychotherapeutical work to work through the fact that you were abandoned by your father and then your mother. Otherwise, you are right to say that you will not see him for the next ten years. He said to me he took his stuff because he did not hear you say, that there would be "place" in your next home for him.

THIS WORK HAS TAKEN PLACE, ALTHOUGH I DO NOT MAKE A BIG THING ABOUT THIS. THE PROBLEM I HAVE RIGHT NOW IS NOT TO DO WITH THIS ASPECT OF MY LIFE BUT WITH MY CAPACITY TO CONTINUE TO "PLAY THE GAME". I BELIEVE THAT AT SOME POINT SOMEONE MUST GIVE EDWARD A CLEAR MESSAGE THAT WHILE HE CONTINUES TO BEHAVE IN THIS WAY IT IS IMPOSSIBLE TO BUILD A STABLE REWARDING RELATIONSHIP. HE NEEDS TO REALIZE THAT THE WAY HE BEHAVES DOES NOT FOSTER LOVE. I AM ALSO AT THE LIMIT OF MY ABILITY TO COPE WITH A CHILD THAT I CANNOT CONTROL AND WHICH I AM SOMETIMES REALLY AFRAID OF (IN HIS REACTIONS AND ABILITY TO HARM HIMSELF

AND OTHER PEOPLE). HE HAS TO REALIZE THAT MY HOUSE IS NOT OPEN TO PEOPLE WHO THREATEN BEATRIX, MY WIFE AND THEMSELVES. HE CANNOT SAY THAT HE WILL KILL BEATRIX AND JUDITH AND EXPECT ME TO WELCOME HIM. HAVING SAID THIS I CAN UNDERSTAND YOUR OWN PROBLEMS IN THIS RESPECT BUT THINK THAT WE SHOULD AGREE THAT THE PROBLEM IS NOT WHETHER YOU OR ME ARE BEING GOOD MOTHERS OR FATHERS. I THINK THAT WHAT WE ARE BOTH ASKING FOR, ALBEIT FOR DIFFERENT REASONS MAYBE, IS PROFESSIONAL HELP, A STRUCTURED ENVIRONMENT FOR HIM AND A SUPPORTIVE MECHANISM THAT WILL ALLOW HIM TO DEVELOP ESSENTIAL LIFE SKILL.

I have told the UCA and the SMP that if they think it would be good for Edward to include you in sessions and so on, then they do so, but I do not want to hear anymore about Edward not having a strong father role model and isn't it a pity.

I AGREE WITH YOU BUT THIS IS ALL PART OF THE GAME THAT IS BEING PLAYED AND IT COMFORTS ME TO SEE THAT YOU ARE ALSO MOVING AWAY FROM IT.

I have come to the point where I have asked for others to help me to help Edward. I do not want to be his school counselor, his father and his mother all rolled in to one. I just want to be his mother. And with the help and support of others, that is how I intend to change my role. I will not ask you for help (as much as I can avoid doing so), but I will not go out of my way to keep you informed. The doctors and nurses can do that.

THIS IS FINE, YOU NEED TO TAKE SOME DISTANCE, I CAN UNDERSTAND THAT. I THINK THAT WHEN PEOPLE SAY THAT YOU HAVE DONE TOO MUCH IT IS BECAUSE WE HAVE SEEN YOU TAKE ON ALL THESE ROLES, PLUS NOT REALLY GETTING REWARDED FOR IT FROM EDWARD'S PART. SO IT IS PERFECTLY OK TO BECOME THE "SUFFICIENTLY GOOD MOTHER".

I went with Beatrix to visit Edward at Glycines yesterday. It wasn't as bad as I remembered it. I understood that the UCA team would be going over this

morning to do an evaluation and that Edward will most probably return to the UCA before the weekend.

I TALKED TO HIS DOCTOR AT THE GLYCINE AND MUST SAY THAT HE IMPRESSED ME BECAUSE HE HAD ALREADY A GOOD UNDERSTANDING OF THE PROBLEM. HE MADE IT CLEAR THAT THIS PLACE WAS NOT ADAPTED TO EDWARD BUT ALSO SAID THAT HE THOUGHT THAT IT WOULD SERVE AS A REMINDER TO HIM THAT THERE ARE RULES AND THAT BREAKING THEM HAS UNPLEASANT CONSEQUENCES.

I am working hard at finding a short-term solution (activity, maybe go and stay with someone) to take care of him when he comes out so that he will be in security before the centre du jour can take him on. I should have a date for the centre du jour when I go back to the SMP on Monday.

I don't care if you and Jean-Luc think I have been an over-protective mother and have smothered him. When I go over his scholastic history, I was the only one who was there to pick him up, to help him along, to encourage him and to protect him from all those pedagogical ass-holes, and un-knowledgeable professionals, who could only blame him for being stupid, for being lazy, for not pulling his socks up, for not being as good as he should have been. And right now, if I wasn't continuing to be there, who the fuck would be there for that child? The service de la protection de la jeunesse?????? Wow, what a replay of history! Yes, being a parent is difficult. Kate

E-mail to Richard on August 23, 2001:

I had a good talk with the psychiatric nurse yesterday about medication of the teenagers.

She said:

- 1) if you start with medication at teenage time, where do you go from there?*
- 2) they consider adolescence to be a difficult period where therapeutic help and support is required; psychiatric diagnosis of potentially other psychiatric illnesses is therefore deferred until age 20-22.*
- 3) they consider that medication has a "doping" effect which can cover up the underlying causes and make therapeutic work slower. It can also be that the doped person thinks they are doing so well, they don't even need therapeutic help.*

4) if after 3 weeks in the crisis unit, the teenager is not moving forward (i.e. learning how to express themselves without reverting to temper tantrums, etc.) and is potentially in danger of getting out of control (moving towards suicidal thoughts, extreme violence, etc.) then medication is considered.

Edward had a violent temper tantrum yesterday morning and was forcibly removed to the psychiatric hospital. He is no longer interned on a voluntary basis. However, the Crisis Unit is going round this morning to evaluate the situation, and hope to take him back on in the Crisis Unit today. I saw him last night. He is not being medicated. They are sort of showing him that even professional helpers cannot contain his temper tantrums ("Oh, Mrs. Lindley, we think we saw what you have seen a lot of...") and that if he puts himself in danger (he threatened to cut his veins) then he will be under 24 hour supervision and his freedom curtailed. He admitted to them that he usually obtains what he wants by having a temper tantrum! However they are listening to his distress.

Psychiatrists can't be wrong, eh? Well here is one person who is giving them a good going-at! They also said yesterday they were partly responsible for the fuck-up last week. So I told the nurse that I hoped that the place where the stupid doctor went on holiday to was having rainy weather. She said to me, "Oh, you really hold it against him?" to which I replied, "To some extent, yes, but if I really hated him then I would want him to be on top of the Etna." What's a bit of rain?

Can a psychiatrist drown in the rain? Yes, if pushed under by Kate.
It could be worse. The sun is shining.

Entry in the family calendar on August 30:
Edward is coming home!

Entry in my diary on August 31, 2001:
*Edward came back and by night time it seemed that everything was back to usual.
And this morning my stomach and back are hurting again.*

E-mail from Rose on September 3, 2001:
Supportive thoughts and greetings Kate. I hope you're keeping your head above the stormy waters. You do have hard adventures! I admire your tough persistence, and looking after yourself before you go completely down the plughole, though I expect it feels like you're trapped in the whirlpool.

I hope the crisis unit enables Edward to start re-evaluating and finding ways to get his needs met other than his temper tantrums and self-destructiveness. The unit sounds the sanest I've heard about, but a hard task.

One of Richard's aphorisms is Love is Caring plus Ruthlessness - makes sense but not easy to carry out.

Anyway keep hollering and laughing and anything else you need to do, and appreciate yourself as a splendid human being.

E-mail to Rose and Richard on September 13, 2001:

Edward is out of the crisis unit and waiting to go into a day center for adolescents. However, we keep being told that he will be admitted in two to three weeks, so I am losing confidence.

The other day I found I could cry in front of the social assistant, and I could tell her that I am losing confidence, and that I am scared for Edward's safety and well-being. I don't cry with manipulative intent - but it sure does disarm the social assistant. I told her that she can maintain that she is "right" when she said that he wouldn't be able to go until end September, when I had retained the idea that he would go mid-September, but her being right doesn't make the situation "better". I know that she usually has to deal with a lot of my anger which I have for the medical and health professionals, but she started acting just as bloody superior as the rest of them.

But bit by bit, things are falling into place. Edward is doing ok as long as I keep to just taking care of him simply (dinner, clothes, pocket money, time to come home). I cannot mention anything like occupations, current or future, cause then I start putting expectations on him and he gets really upset. They finally put him on a low dosage of a psychotic drug, Risperdal, just before he left the unit. One mg in the morning and one mg in the evening. We went to the circus last night - with Beatrix - and had a really good laugh together. Nothing like laughter to unite!

E-mail from Rose on September 18, 2001:

Good to hear about the circus, we all need to laugh more for it's healing power, and as you say laughing as a family is uniting. I assume I sent you the summary of the laughter research review. I've just done a couple of laughter workshops for women in Aberdeen. Only three hours, but a good chance to try things out.

Participants were pleased in both, and in the second I got as far as illustrative bits of using Tee Hee! and ridiculous contradictions on distresses.

My summary says that any way of increasing the amount of laughing done is beneficial for it's physical and mental effects, (films, books, comics, etc) and finding ways of laughing about distresses and patterns (DERs in chapter) means great leaps forward in dealing with distress. I wish there were more Annette's around - she works with disturbed children as well as all adult work - as I'm sure that would help Edward.

Good that he's out of crisis unit, though you're right to be upset that he isn't going immediately into the day centre as he needs ongoing support and care. Unfortunate about the Risperdal, which is being used as a substitute for proper care. Yes, I fully recognise that some ways of helping him control the acting out and damaging behaviours he has is needed, but neuroleptics are an exceedingly dangerous answer.

Richard says Risperdal is a newer drug, touted as fewer side effects and can be given in smaller doses because it is more potent. What this means is that it will take longer to cause liver damage and any other effects where numbers of foreign molecules are involved. However the other damaging effects are proportional to the potency (and length of use), so you are not gaining in this area. The rate of the toxic effects is horrifyingly large - 30 % and more.

There are two other considerations. Firstly the neuroleptics (anti-psychotics) are not ways of treating the distresses, they are ways of controlling the symptoms, which may allow other help to be given, but they are typically used instead of other help. They also interfere with therapy treatments, and cause cognitive deficits. A major problem is the so-called "beneficial effects" are the same as the unwanted "side-effects".

The characteristics of any of the mood altering drugs are that they alter the immediate relationship between pattern triggers and response. This cannot be a long term solution unless this results in behaviour which directly contributes to solving the problem. This is unlikely. When this doesn't happen larger doses are needed to get the same effect, bringing on the unwanted effects sooner. Typically these are controlled by giving other drugs, having even more physically nasty effects in the long run. Also however the relationship between*

*mind and body and what's happening in your life becomes chaotic.
[* Found an interesting discussion I'll get Richard to send as it's on his machine.]*

In addition to the dangerous effects of neuroleptics (totally unacceptable in any other branch of medicine outside psychiatry) there is evidence that they interfere with the chances of people living a normal life in the future. Research comparing people put on drug treatment, with those given custodial care while they were having 'psychotic episodes' shows that with drug treatment the chances of being hospitalized in the future increase, and the chances of being able to live an independent life and hold down a job decrease.

There is evidence that a third of those who have psychotic episodes never have another in their life. Once on drugs however this third disappears, i.e. many of the effects attributed to the 'illness' are actually drug effects. This is partly the effects of our current medical system where the beliefs are that the drugs are curative or essential for managing the 'illness' and the links with emotions are not understood. A particular hazard is coming off the neuroleptics (also applies to tranquillizers, SSRI's as well) When the dose is reduced too quickly, the reverse effects to going on the drug occur - very rapidly - the damping of the emotional responses is removed and system goes haywire - mimicking the original distressed behaviour. Although it is possible to distinguish between such 'discontinuation effects' and original symptoms and behaviour, most medics or psychiatrists do not have experience or skill in this area, so it is often taken as a sign the person cannot operate without the drug, and they're put back on.

Research and experience of therapists who work to take people off the 'mood changing drugs suggests effective processes are very slow with very small reductions needed and the person helped and supported while they adjust. This is months or even years for example with major tranquillizers. This means a higher potency one will cause more problems on attempting to stop it. This doesn't say Edward is regarded as having a 'psychotic' episode at the moment, but the drugs don't care what the diagnosis is. He is clearly in need of help in a major way. You providing him with care and support is important, he needs his family. However as illustrated by the fact he doesn't want to talk at all to you about issues in his life, you are also part of his problems. No blame implied, no-one can act as therapist to family members, I think you've been

doing a terrific job as a mother, having set off with many handicaps and certainly not helped by John – well, this last phrase is British understatement. Anyway I would certainly inquire about how Edward gets to come off the drugs, and how they do this, and what individual therapeutic help he is getting/ will get.

Arising from our experience and emotional models, Richard and I think Edward might do best with therapy which is physical and expressive rather than just verbal, or behavioural. This comes from the distresses on top for Edward at this point being Acting Out ones, with aggression directed at others and himself. [Not saying these are all he has to deal with, and opposite ends are going to be despair type] This means they are difficult to get at when patterns not running, and when they are running thinking is impossible. The acting out patterns need safe interruption to work with them. More temporary control, though real control, can be achieved by physical interruption of the internal arousal which fuels them. This can be physical exercise, so if Edward can be persuaded to increase physical exercise - preferably whole body co-ordinated exercise- this will be helpful overall. Again this probably needs supportive people for him to do it with, which might be at a gym. Important that he isn't doing totally exhausting exercising though. Being able to exercise when he starts to feel lousy can become a control method. Not an easy option, needs equivalent support to other forms of therapy, but viable.

Thoughts about physical therapists - people trained as Bioenergetic therapists and this seems to me worth trying. I'm not sure if such training/people still exist. [Daniel Le Bon in Belgium used to insist people who wanted to join the Re-Evaluation community there did Bioenergetics courses first, and I can see the point about that - CCI co-counselling has certainly degenerated into being talking head stuff a lot of the time. There is something called Feldenkrais method which incorporates the physical side in similar ways I think, though gentler.

The other aspect is Art and or Music therapy which in which the person is expressive and gets to unload stuff, and talking comes out of this. Expressiveness (physical and emotional), which helps emotional reset, is the major factor shown by a lot of research on children and adults to be associated with physical and mental health. This shows despite the fact the researchers didn't have a model which distinguishes healthy from distressed expressiveness

(acting out). This is indicating the strength of the effect and how it is the natural way for human beings to be. We need opportunities to release unwanted emotional arousal, and we're taught to restrain this at an unhealthy level.
Much love and hugs, Rose

E-mail to my father on September 29, 2001:

Edward started the therapy day center on Wednesday. We had an hours talk with the doctor, the social assistant and the psychiatric nurse, Gerald, who is Ed's assigned helper. During the first two weeks they will do an assessment and then we meet to discuss the objective of his stay, and a "project" that he will be working towards. The doctor picked up and pointed out that twice Edward said that his opinion differed from mine (which he thought was positive, because he did it calmly, and because it showed he could say to me that we differed). We discussed the temper tantrums, and the doctor asked Ed if he was aware that people were afraid of him - he said that was something that they had to work on, but that would mean understanding why he got so frustrated and that obviously has links to other things, like feeling inadequate compared to his sister, not having the school knowledge. I really insisted that Edward's cognitive capabilities would change and develop with the hormonal treatment (they looked at me unbelievably) so finally we agreed that the doctor would call the endocrinologist for further information on the syndrome and Edward's development.

He likes it there. He is not sure why he is there. He goes full time, which is 10:30 to 16:30 everyday. But it is better than hanging about!

Email from Richard on October 7, 2001

Gather Rose told you I'd come across an on-line paper by a psychiatrist critical of the 'chemical imbalances' model. She has now - - 'nagged' is my experience - - ENCOURAGED me to send you the url. This is a paper titled "A reevaluation of the relationship between psychiatric diagnosis and chemical imbalances" by a guy called Sobo. The url is: home1.gte.net/engeseth/ssobo.htm

Her encouragement came because I was telling her of an item in an email discussion group I'd read this morning. It was posted by a bloke in England who runs a large NHS clinical psychology unit. He said (edited only to remove names) that when you're told your child/partner/parent/friend has an organic brain disease you might try the following:

"X's account has prompted me to write a brief piece for Openmind (Britain's main psychiatric service user focused magazine) advising patients, advocates and relatives what to do when told they, or their loved ones have an organic condition. Quietly and calmly they should say, "Please can I see the blood and other tests you have done to indicate that there is a brain problem?" If stalled, they should say, "Please arrange for the tests to be done and we'll be back tomorrow."

E-mail to John on October 10, 2001:

Edward has asked me to tell you that he would like to call the sailing off for this weekend. I don't feel very happy about being the messenger, but he asked me to tell you that he is upset about your relationship and thinks that it would be best not to see you after all. We had a session at the centre du jour yesterday which was very emotional and difficult. He has started two sessions a week with his therapist too, so he is getting lots of support. Dr. H. has proposed three months therapeutic treatment at the centre du jour, and then addressing his future orientation. He said that Edward is having to come to terms with lots of very difficult things for himself about his childhood, his syndrome, our divorce. He told me that he needs lots of being listened too. He has to learn to put up boundaries, say no, find the right distance between himself and others, including his friends. I am in shock from what I have heard. I don't think it is appropriate for me to repeat it, but I had no inkling of how much he is suffering.

John's e-mail reply to me on the same day:

I am sad about Edward, he seemed so enthusiastic about going out and since he suggested it I felt that he was coming to some sort of equilibrium. I will call him tonight and get the temperature. Maybe he is feeling bad because he caught me at the wrong moment a couple of times on the phone during the day.

Letter from Mrs. B. S., Cantonal Office of Disability Insurance, addressed to Berthe, Edward's psychotherapist dated October 10, 2001, translated from French:

Subject: Edward

At the request of Mrs. Katherine Lindley, we are sending you, attached, a copy of our report dated June 23, 2000, from our division of professional Re-adaptation.

I was not allowed to have a copy of this report, according to the AI representative, which is illegal, but I was allowed to request that Edward's psychotherapist was given a copy.

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Cantonal Office of Disability Insurance (Assurance Invalidité / AI) Geneva, March 27 2001 Report of the Division of Professional Re-adaptation Name: Edward AI File : Personal details : AI Number: First signaled: September 20, 1995 Attribution: May 17, 2000 Medical doctor: Dr. P-C. S., pediatric endocrinologist Type: Report Date: 23 June 2000
<u>PROPOSAL</u> Proposal to be defined later. Our insured person is currently doing a year of pre-apprenticeship at the SGIPA until June 2001. According to his mother, a new diagnostic was established in the month of February which totally modifies the situation. Edward does not suffer from hyperactivity disorder, but from Klinefelter's syndrome. He is following a new treatment, which should rapidly modify his mood and intellectual capacities, according to the words of Mrs. Lindley. We do not currently have any medical elements which confirm this factual state. Mrs. Lindley has filled out a new request for services. We leave it to you to complete the medical report of this file and to verify the implications of this new diagnostic on the schooling and professional training of our insured person. Following that, it is necessary to transmit this file to a psychologist for a new assessment of the insured person's intellectual capacities and his professional orientation.
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<u>CONTACTS TAKEN</u>
Mr. B., teacher, SGIPA, telephone interview on March 6, 2001: Edward passes through different phases. He is relatively calm, but has explosive moments. Concerning the school subjects, he is absolutely not motivated. He

has a totally avoidant behavior. With him, it is impossible to reach the pre-apprenticeship objective. His personal preoccupations are too great. He is not present, he seems to be haunted by his pre-occupations. Mr. B. has the feeling not to be able to do anything for Edward. Edward talks of doing photography, but doesn't take any photos. He requires a more individual structure with a psychological accompany. Currently he is too preoccupied to be able to invest himself in something.

Mr. S., Mrs. Lindley's partner, telephone interview on October 25, 2000: Edward was expelled from Maya-Joie during the month of September. They are currently looking for something less academic. He has looked into the Workshop-Class FJO but they don't have any place.

Mrs. B., Edward's psychotherapist, telephone interview on July 18, 2000: Edward has made a lot of progress recently and it is important that he do another year at Maya-Joie. He is in a period where he reflects and takes responsibilities. There is a certain slowness in some aspects of his personality. He is very sensitive with an artistic tendency.

Mr. E.R., director, Maya-Joie School, telephone interview on May 24, 2000: He is not opposed to Edward doing another year with them, contrary to his former opinion. Effectively, Edward has worked hard recently. Within the frame of prolonging his stay, the idea is to create a tailored program with a higher level of expectations in English, and less demanding in other subjects. Edward is currently following 7th grade, although he should be in 9th grade according to his age. He has accumulated certain deficits because of his psychological difficulties and his difficult relationship with his mother. He is still very immature and is not ready to start a professional apprenticeship from either a scholastic point of view, or a psychological point of view.

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STATE OF HEALTH

Diagnosis

- Decrease (probably congenital) of his adaptive capacity to his environment (congenital behavioural disorder)
- Sequel of an accident with cerebral commotion in 1992
- Coincidence of the two

Beginning of illness: No indication

Evolution: improved

Doctor: Dr. L.P.L., psychiatrist and psychotherapist, Geneva (Medical report of December 5, 1995)

Diagnostic: Verbal language learning disability

Beginning of illness: No indication

Evolution: No indication

Doctor: Dr. C.A., psychiatrist and psychotherapist for children and adolescents, Geneva

(Medical report of July 8, 1992)

LIMITATIONS:

a) **Physical**

According to the insured person: According to our interview with Mrs. Lindley, Edward's mother, on March 6, 2001

Until now, we thought that Edward had a diagnosis of ADHD. But, since this year, Dr. P-C.S. established another diagnostic, that of Klinefelter (congenital disability). Edward started hormonal replacement of testosterone on February 23, 2001. After three months, changes should start to appear on the levels of mood and mental development.

According to our office: Edward is a slim boy who is very tall, which makes him appear older than his age.

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b) **Mental**

According to the insured person: From our interview with Mrs. Lindley on March 6, 2001:

Edward is currently very depressed. He has the feeling that his father does not want to see him. He understands that a new diagnostic has been made. He should be looking for internships during his free time, within the framework of his pre-apprenticeship year at the SGIPA, but he isn't doing it.

From our first interview with the insured person and Mrs. Lindley on June 27, 2000:

During this first meeting, Edward talked very little. Mrs. Lindley explained to us that he was following a 7th grade program at the Maya-Joie school, although he should be in 9th grade. She told us that he suffered from ADHD, which leads to learning difficulties. He also presents a slight dyslexia. Different treatments have been tried. The last one, was a phosphate-free diet. He has had many difficult experiences in schools and has been expelled often. According to Mrs. Lindley,

Edward feels devalued and has poor self-esteem. He is undergoing psychotherapy with Mrs. B. The year of 2000 was difficult. Additionally, Edward has a tendency to have accidents (falls, etc.) when he is feeling low. He has been to the emergency ward about twenty times.

According to the doctor: According to Dr. D. M. (pediatrician) in a telephone interview on July 25, 2000:

Edward has re-started psychotherapy. He has hyperactivity disorder. He is following a diet and a homeopathic treatment. It is a complex situation because he presents psychological problems. He has been seen by Dr. H. at the Children's Hospital. Ritaline did bring about an improvement, but Edward is not taking it anymore. He is not yet mature. She cannot see how to make any decision about his future. He especially has serious behavioral problems at school, but it is getting much better. He could certainly make intellectual progress. He has to be very loved to be able to work.

According to Dr. E.P.-C. of the SMP, medical report dated January 25, 1999:

... He seems to have started well in his new school and has found reassuring relational markers. Nevertheless, as soon as he cannot cope his way of discharging immediately is to "act out". He openly expresses his difficulty to be separated from his mother, even though he tries to comprehend the necessity. Beyond his academic deficit, on the learning level, Edward seems to me to be concerned and preoccupied with his future, which makes him more open to the proposed learning possibilities.

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According to the medical report of Dr.L.L., psychiatrist and psychotherapist, dated September 20, 1994:

Decrease of his capacity to assimilate the school program and difficulty to adapt to the class environment. (...) The adaptation difficulty compromises the assimilation, which will then have repercussions on the adaptation, installing a vicious circle, that we must interrupt. (...) Language difficulty, has been treated by the SMP since pre-grade infant school. The parents separated the following year. The above-mentioned accident happened several months later, probably coinciding with the circumstances, congenital predisposition and the accident with

hospitalization in 1992 (...) Upon examination, the child is abstract, apathetic, with a retarded attitude, childish for his chronological age. The school information given by his teacher shows behavior seeking conflict, failure and victim status. Pathological anger at times. We also note – without further examination – a language deficit.

According to our office: Edward seems to us a very lively boy, relatively verbally aggressive, showing little respect for authority, especially his mothers. He finds it hard to stay still and compensates for his difficulties with different artifacts (cigarettes, roller skate achievements).

Edward's mother seems to find it hard to accept that her son is not in public school. She wants him to continue in school and thinks that he would be capable if he was given extra means (e.g. a tutor).

STRENGTHS

According to the insured person:

Mrs. Lindley has a relatively ambiguous discourse. She admits that Edward has difficulties at school, but, at the same time, she thinks that he would be able to follow an academic path. She describes her son as a sensitive and very creative person.

According to our office:

Edward is very well supported by his mother, both morally and materially. She is doing her utmost to help him find a socio-professional solution.

SOCIAL SITUATION

Family

Edward's parents are divorced. He has a close relationship with his mother, who seems to have a tendency of over-protecting him. The father is often not present. The relationship between the parents is difficult. Edward has the feeling that his father rejects him. Our young insured person has a sister, 20 months younger than him, who is in Junior High school, Latin section.

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SCHOOL / PROFESSIONAL RECORD

School record

1st, 2nd pre-grade / infant school and 1st and 2nd grade at Satigny Temple
3rd grade in special educational class, Meyrin-Bellavista
4th grade at international school, Collège du Léman, not completed

5th and 6th grade at the Nouvelle Ecole Farny
7th grade at Benedict School, not completed, followed by
7th grade at Passerelle School (special educational needs), not completed,
7th grade at the Maya-Joie School from 1998 to September 2000
Since October 2000, pre-apprenticeship at the SGIPA (Société Genevoise pour l'Intégration Professionnelle d'Adolescents et d'Adultes – Geneva Society for the Professional Integration of Adolescents and Adults)

Languages

Bi-lingual French / English

German: finished his 7th grade with difficulty

Professional internships

A kitchen internship in December 2000

Hobbies

Roller skating and similar sports

SUMMARY OF THE PSYCHOLOGICAL ASSESSMENT

DATE OF EXAMINATION: June 23, 2000

BEHAVIOUR DURING THE TESTS:

First of all, let us mention that Edward turned up with his roller skates for his professional orientation session. He was hardly motivated and seemed to be in a hurry to finish the session. He asked us repeatedly how many more tests he had to do, and told us he had a meeting. During the examination, he had difficulty in interpreting the instructions of the different tests. Often he told us that he had understood, but we realized that it was not the case when we went into more depth. Edward needed constant reminders and could not keep still. The fact that he had to remain seated did not appeal to him. He seemed dissipated and did not concentrate very much, making comments or asking questions during the tests. In spite of this, he was able to concentrate on certain tests, especially those which required face-to-face presence of an adult. We noted that when we encouraged Edward to reflect, he often found the right reply, even after he was discouraged and had abandoned. Edward was quickly fed up with the testing. He was totally demotivated by the math test which he chose to give up after a short period of time.

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RESULTS

1 ABILITIES

The capacity to **integrate and apply instructions** is sufficient. Edward obtained results, which are average compared to pupils who have finished a division of General or Practical in the Geneva Junior High (obligatory schooling).

Concerning **abstract, logical reasoning on non-verbal items**, Edward achieves lower results than the pupils of 7th grade, General or Practical. It should be noted that he gave back his test before the allowed time was up, saying that he found it easy.

In a test of **logical reasoning with figurative data**, aiming at deducing the rules of composition in a series of numbers, Edward's results were very weak.

He was more at ease with a **practical reasoning** test, manipulating pieces of wood, which required also spatial representation. In this test, his performance was average compared to apprentices aged 14-15 years old. In this exercise, he tended to be discouraged when the solution did not appear spontaneously to him, but discovered it when we encouraged him to persevere.

In regards to spatial representation, in a test aiming to organize unstructured visual data into a highly structured ensemble of forms, Edward's results were insufficient compared to pupils who have completed their obligatory schooling in the Practical division.

Edward showed a good capacity in **complex figure perception**, demonstrating good faculty of spatial representation and showing proof of precision in tracing and respecting proportions. His performance was, in fact, in the upper average of 15 year olds and adults' results.

Concerning his faculty of memory, he shows an excellent visual memory; his performance exceeding largely that of young people his age. In the auditive modality, his memory faculty remains good for learning a series of 15 words, although slightly inferior to the visual modality. This performance needs to be highlighted, knowing that it requires an important effort of concentration. His auditive recognition appears to be insufficient.

Lastly, an exercise requiring sustained attention on a simple task was more difficult for him, which is easily explained by his dyslexia mentioned by his mother.

II MANUAL ABILITIES

During an exercise **to make a triangle out of a piece of wire**, Edward showed relatively good dexterity, although he was missing finer precision and perseverance, essentially due to his lack of motivation. He didn't try to improve his work, having been quickly fed up with the task.

III SCHOOL KNOWLEDGE

In mathematics, Edward obtains insufficient results in regards to the basic knowledge requirements of obligatory schooling in the section Modern. He makes mistakes at the level of 5th grade and the 7th grade level is not acquired. We repeat that he was very demotivated and lacked concentration during this tests, which he rapidly abandoned. He also had difficulty in an exercise which required the ability to different arithmetical operational results.

In a test for vocabulary comprehension, that we gave to him orally, his results are average compared to pupils who have finished obligatory schooling in the division General / Practical. Lastly, concerning his spelling, Edward obtains insufficient results in comparison with 7th grade, in a dictation.

IV PROFESSIONAL INTERESTS

The only interest spontaneously given by Edward is to teach sports. In a test, which situates individuals in regard to different categories of professional interest, corresponding also to personality types, the artistic area (characterized by originality, desire to express own ideas and feelings through writing, art, etc.) showed up against the others, followed by the social type (generosity, desire to help, take care of others, educate). The other areas (realistic, intellectual, entrepreneurial, and conventional) were average, none of them were rejected. It should be noted that this test reflects the person's self-perception.

In a second exercise, which consists of ranking different professions, the professions that were marked by Edward were, princIP., those of baker-pâtissier and photographer. After that came professions linked to security (security guard, military instructor, fireman) and those linked to nature and animals (forest-keeper, wood-cutter, animal keeper, wine-grower). Other marked professions are librarian, hair dresser, kindergarten worker, cook, post office worker. The only professions rejected by Edward are those of watch-maker, steward, train ticket inspector, assistant teacher and technical lighting specialist.

SUMMARY

The results of the examination seem to have been strongly influenced by Edward's difficulty to concentrate. He also lacks self-criticism and his behavior is relatively immature. He has to be constantly encouraged and structured. He has an excellent memory, in particular visual memory. He showed high precision in tracing a complex figure. Edward has a relatively good manual ability, but lacks in precision and perseverance. His reasoning capacities are better when the focused on concrete and practical supports, rather than abstract.

Lastly, he showed a good ability of vocabulary comprehension. In comparison, his performance and results were low in mathematics, spelling, and spatial domain. In the scholastic field, the level of 7th grade has not been acquired.

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DISCUSSION

Edward, aged 16 years old and bi-lingual French-English, has had a relatively chaotic school career. He has been expelled from different schools. He was given for several years special educational measures, as well as pedagogical-therapeutical measures. Since September 1998, Edward has been enrolled in the private school Maya-Joie, where he started a 7th grade program.

We met Edward in the month of June 2000 to propose professional orientation. During this meeting, his mother informed us that he suffered from hyperactivity disorder. She told us that she hoped he would be able to follow a school program. However, our psychological assessment shows that the 7th grade school level of mathematics and spelling has not been acquired. When we told Edward and his mother the results of the tests, in the summer of 2000, it was foreseen that he would do another year at Maya-Joie, and follow the 8th grade program. The question of his orientation at the end of this school year is open. With the idea of prolonging his school career, as Mrs. Lindley is hoping, the BER school proposes a 10th grade, which covers the programs of 7th to 9th grade. But it should not be forgotten that Edward has redone three times his 7th grade, which leads to believe that prolonging his school career is not the best solution. Another alternative is that he does a year of pre-apprenticeship, designed for pupils who have reached the level of 8th grade, but have not graduated at the end of the 9th grade. The Workshop-Class FOJ offers such a program. This program is also very well structured, which seems to be indispensable for Edward.

It was agreed that we would contact Mrs. Lindley again in the beginning of 2001 to discuss the additional year at Maya-Joie. However, in the month of October 2000, Edward was expelled from this school and was enrolled in the pre-apprenticeship year at the SGIPA. In the month of January 2001, Mrs. Lindley told us that a new diagnostic had been made, that the diagnostic of ADHD was misleading. Edward suffers from Klinefelter syndrome and had started a hormonal replacement treatment at the end of February. According to Mrs. Lindley this treatment should rapidly bring about modifications of mood and intellectual capacities. We do not have any medical elements that confirm this factual state. During our telephone interview of March 6, 2001, with Mr. B., the SGIPA teacher-supervisor, he informed us that Edward was not in the right

place in this structure. He is very immature and shows no interest in school subjects, his personal preoccupations stop him from investing himself totally. Mrs. Lindley has made a new request to our insurance on February 13, 2001, following the new diagnostic. It should be noted that she wishes that her son should have special educational assistance, even though his previous experiences have proven to be inconclusive. It should be reminded that he will be 17 at the end of this year. Considering the particular situation linked to his medical treatment, it would be appropriate to review this file on the medical level and to verify the implications of the current syndrome on his education. It would be useful for Edward to be seen by a psychologist before the end of May, in order to propose an IQ test. A possible solution for the new school year would be an internship at the 18/28 Workshop of the CIP. (Centre d'Intégration Professionnelle – the Center for Professional Integration).

Letter from Dr. H., psychiatrist, at the Therapeutic Day Center, undated, translated from French:

With this letter we inform you that unacceptable events have taken place at the center these past few days which compromise the smooth running of the dispensed care.

Your son has participated in the form of repeated insults, intimidation and threats addressed to the staff. We have to inform you that if these behaviours should be repeated, then we will be obliged to envisage a temporary or definite exclusion from our center.

E-mail from my father on October 12, 2001:

Thanks for the email with news of Edward's progress. Feel a bit like an onlooker but one who is very concerned since you are family, flesh and blood. Can't do much to help except to pray.

E-mail from John on October 22, 2001

I realize what you are going through and have no words that can really help. I was horrified yesterday when I called back Beatrix and heard Edward's voice, it was slurred and he was half asleep at 2 o'clock in the afternoon. From my point of view I really feel that you need to let go of E and seek professional care for him. I know I am being hard and that you must feel a lot of responsibility. Beatrix tells me often that she suffers from the attention given to E and she is crying out for recognition. Although I realize that I am not being very supportive at this time I am always available to talk to you and want to help not

hinder in any. If you prefer me to take a more background role towards Beatrix I will.

Extract from my response to John on October 22, 2001:

I have two temperamental teenagers to deal with 24 hours a day, 7 days a week. I hardly get a break. Please don't make my life more difficult than it already is. I could cry I am so over-loaded. Kate

Entry in my diary on October 27, 2001:

Always doing what the others want me to do. ... A relatively OK day on my own. Went to the health club, the flea market, the hairdresser, Migros supermarket and went to see two new episodes of Absolutely Fabulous.

E-mail from Rose on October 30, 2001:

Borrowing from Petra to say I'm delighted to hear of your success and I hope you keep enjoying that you did it for months to come. And good for Jean-Luc too that he could support you smartly at the point you were going to give up. Take time to de-stress - hopefully before the next crisis.

All power to your elbow in dealing with the health professionals - a long hard struggle I guess, but sounds like you keep making some progress. Tough on Edward though (and lots of people) that our system is so crap.

E-mail from Rose on October 31, 2001:

I like hearing about you living your life, and when you're bravely tackling your patterns I find it gives me a nudge to emulate you. What a weekend you had - great work. The range of feelings isn't surprising. I find that when I'm trying to tackle ways in which I put myself down or feel inadequate I have a lot of grief for the me that has been hurt and stifled. While I get to do more of what I want I find it hard to feel easy about it a lot of the time - it feels selfish and if its directly competing with what someone else wants I find it difficult to maintain a sense of I'm OK.

You've reminded me of my major 'do it by myself' - I did my first solo walk, 16 miles around the Edale valley watershed on my 40th birthday. It was interesting and scary and I was very pleased to discover I didn't need to rely on anyone except myself. After that I took opportunities to do other solo walks - great sense of freedom not having to take anyone else into account, as well as being

able to look after myself. Haven't done anything like that for a long time. There's a sense in which it's easier to do something like that than tackle how to decide and do more of what I want in everyday circumstances. The best laughter lines come from finding the words the distress supplies and going for the ridiculous opposites, so worth writing down all the relevant distress words about doing things on your own. Your general description of your pattern made me think along the lines of developing your inner friend, as in developing inner counsellor or inner coach, as in the Digital open learning package.

"I'm my own best friend." "Having others around is a bonus not a necessity."

"I'm rooted in relationships so I can grow on my own."

The other thoughts are about separating frightened Kate (one of your internal little girls) from current smart, intelligent, creative Kate who can look after the frightened little girl. Applying this to me I need to look after my little girl who could never get it right, so is always inadequate. Thanks for the reminder.

Entry in my diary on Saturday, November 3, 2001:

A week's gone by. Angry, angry Monday. With Jean-Luc, I do feel there is an imbalance of taking care of each other. He takes care of himself, and I take care of him. I don't take care of myself and neither does he. Maybe his anger comes up because "he doesn't want to change his lifestyle".

Entry in my diary on Monday, November 5, 2001:

After a weekend of doing a creative expression, Art Cru workshop, anger and unhappiness again.

Entry in my diary on Friday, November 16th, 2001:

Last night I came home late from teaching and Jean-Luc had arranged for us to go and eat foie-gras at Sylvies. During dinner he tells them how I cling. I tell Sylvie how I admire the way she does what she wants, going out without René. René asked me if I was frightened at being abandoned.

I don't have a partner anymore. I have a boring, old husband, a man who makes no effort for our relationship, who has his little routine in life and who is content. I don't understand why I became the punching ball. If I understand correctly he wants me to get off his back, which I've started to do, and he criticizes me.

We went on a weekend trip to London with Edward and Beatrix to celebrate my mother's 70th birthday on November 16th.

E-mail to my parents on November 19, 2001:

Thank you so much for the wonderful weekend. It was so good to be all together and to have some fun.

Hope you got home safely. Our flight had a half-hour delay, but we were home for 10 p.m.

A little tired this morning, but feeling good. Haven't felt this good for a long time.

Entry in my diary on November 19, 2001:

Had a wonderful weekend in London. And I come back and start fighting with Jean-Luc. Why doesn't he leave me alone?

Entry in my diary on November 21, 2001:

Evening. Two days of course which I enjoyed. I even felt "I don't want this course to end. I'd like to stay here." No sign of JL for 2 days and no wish to see him. Rather a desire to avoid seeing him at all. During the course I thought it would be a possibility to go and see Dr. A..

Extract from my e-mail to my brother, Matthew, on November 22, 2001:

My psychoanalyst told me she attended a Jungian course on Saturday given by a man who said that the best person to teach a young man about being a man is the mother's brother!!!!!! How did you find Edward this time? I know that we set each other off still quite a lot.

Matthew's response:

Would you really want me to teach Edward?? It's difficult to comment about Edward as it's the first time we've seen him since his condition was diagnosed. In some ways he was a typically difficult teenager at times but there is still a lot of anger. It's the way he reacts when he is angry which is disconcerting. An example of something I noted was his surly behaviour when having trouble deciding what to eat in the restaurants which if he can overcome would make things much easier for you all. It was not clear how much they enjoyed the weekend.

Entry in my diary on November 23, 2001:

Talked with Franco. He says that Jean-Luc has imposed his idea of a relationship and I have gone along with it. He says it doesn't sound like Jean-Luc is ready or willing to make compromises with me. He says I have to make my decision and prepare myself to leave. I don't believe it. I can't imagine that this is really happening.

Entry in my diary on November 25, 2001:

Today Fiona called and had a long talk. She said Norbert recommended when people were hesitating about separating, to actually separate and then go out and drink champagne to celebrate. And talk of all the good times. Then go separate ways and see what happens.

Card from my mother dated November 21, 2001:

Dearest Kate, Edward and Beatrix, Thank you all for coming over for my birthday. A special thank you to Kate for helping to bring my dream two-thirds true. I felt really tearful when I said goodbye to you at Victoria. I was so happy. Bless you all. Now it's countdown to 80. Love you all lots. God Bless, Mum and Dad

E-mail to my mother on November 27, 2001:

I don't know if we will go away. Jean-Luc and I have been through a rough patch. Out of the past 5 weekends I have only spent one with him, by my devising, cause I just find, "the nicer you are, the worse he behaves". Anyway we are having dinner together tonight cause it was 8 years ago that we 'declared our love' (no, we didn't sleep together, we waited until the next day!) But I don't cook supper for him these days ... However if we, the four of us, stay at home over Christmas, we, the two of us, may go away for a week in January (low key, no pomp) and maybe I would ask you to supervise B&E for a week. Let me know if you think you could – honestly- I don't want you stressed. In the meantime we will have to plan another weekend in London. Daddy could accompany Edward to the Playstation Skate Park in Notting Hill and us girls could meander along Ken High Street!

Entry in my diary on November 27, 2001:

I invited Jean-Luc to have dinner to celebrate 8 years since we told each other we loved each other. Went to the Café du Centre. A snappy evening. Came home at 10.15. Went to bed feeling tense.

Entry in my diary on November 30, 2001:

Lunch with Chantal. We talked non-stop from 11:30 – 14:00. She too has husband problems. Refused to go for dinner with Tita and Alec. He went alone. I drank champagne with Sylvie and René and talked until 10:00. then went to McDo's with Edward. Bea is in Paris with John.

Entry in my diary on December 1, 2001:

I sit here and wonder what I should do. We've just had a fight. So we're spending the weekend apart. ...

Jean-Luc came downstairs and said sorry. We went to the chalet together. Bea went to Bulle, Edward stayed at home.

Extract from an e-mail to John on December 12, 2001:

Edward had his birthday party last Saturday. We had about 15 sulky teenagers here for a disco. They were great, so was Edward. He had the living room back into order by Sunday morning. No fights, no crises. New girlfriend called Alexandra who is partly Asiatic, not as beautiful as Beatrix, (who could be?) but pretty. I gave him a hifi system. Are you going to see him for his birthday?

Extract from John's response on the same day:

You will certainly be nominated for the Teenager parent of the year.

On the evening of December 21st, we celebrated Christmas with Sylvie, Julie and René. We had supper with them upstairs. Alex (Alexandra) came around to see Edward and they stayed downstairs together. After the dinner, I put his presents outside his door, and wished him goodnight.

The following morning we were leaving for New York. I came downstairs at 7:00 and woke Beatrix up. When I put my head round Edward's door, I saw two heads on the pillow. Alex had stayed the night. I asked Edward to come and see me in the kitchen. I asked him if Alex's mother had given her permission to stay over and he said that Alex had not called her mother. I told Edward to call her

immediately and let her know that Edward was bringing Alex home. Alex called her mother and her mother insisted on coming round to pick her up. I told Edward to accompany Alex to the car and to apologize to her mother for not letting her know.

We went to New York and stayed at the Mark for Christmas. We went to a deli for Christmas lunch and then went to see the Special Christmas show with the Rockettes at the Radio City Hall. Jean-Luc flew home earlier and I went to stay with the children at my sister's home near Philadelphia. We travelled back on December 29th so that Beatrix could spend New Years Eve with her father, and Edward with Alex and her parents in Crans Montana.

I called Alex's mother and apologized for the situation. She told me that she was used to Alex staying out at night and not telling her where she was going. I told her that I thought it was important that we insisted that they kept us informed of their whereabouts. I told Edward that he had to ask permission for Alex to stay over at our place and that she had to ask permission from her mother to stay over.

A greeting card from Berthe dated December 28, 2001:

Thank you for your wishes. I was so pleased to receive the photo of Edward and his sister. It is really a great photo. I wish from the bottom of my heart that this year will bring Edward more peaceful reassurance, the possibility to assert himself and to develop. I wish that you will advance in your projects and lots of joys of all kinds. Best wishes.

2002, the year I tried to give up

Entry in my work diary on January 8, 2002 : 10 :30 meeting at the CTJ (Centre thérapeutique du Jour – Day Therapeutic Center)

My diary entry on January 10, 2002 :

I asked Mummy in a letter if she would come and look after the kids for a week at some point. She called me on Jan. 1 and said she'd love to come. I called her on Monday and told her we could leave on 17-24 January . She has a doctor's appointment for the 17th.

And Jean-Luc is so fucking unsupportive. Starts complaining about his vacation.

E-mail from John on January 11, 2002:

On another note, Judith and I have decided to terminate our marriage, as you may imagine I am feeling both a form of sadness and "relief" after so many months of uncertainty.

E-mail from my sister on January 11, 2002:

I am jealous, a trip to either Cairo, Dubai or Nairobi sounds fantastic. Good for you to get Mummy to come over. I am planning a trip to New Orleans for Steve and myself for his 50th. I am trying to get a teaching assistant to come and stay with Misha and the kids ...

Good luck with the sleep-over girlfriend problem. I am glad I am not in your shoes. I am afraid in theory I would not accept it, but who knows? I also shudder to think that she is the same age as Beatrix and Esther. Thank God Esther is not dating yet ...

Have a fabulous time with your man – you will probably have a great time reconnecting!!

The sleep-over girlfriend problem was Edward's girlfriend, Alex, who had slept over in December, was 15 years old. From the way I remember it today, in 2011, there were three issues. The first was that Alex was sleeping over, staying away from home without asking permission from her mother, or informing her. Equally Edward was neither asking permission for her to stay over or informing me. The second issue was that Alex was legally under age to be having a sexual relationship. Swiss law states that young people, over the age of 16, are allowed to have sexual relationships; however, the law does not prosecute the person in a sexual relationship with a young person under the age of 16, if that person is less than two years older. Edward was less than two years older than Alex, and it became obvious later in the year that her parents did not take offense with Edward for having a sexual relationship with their daughter. The third issue was for me, personally, on how I wanted to deal with my son having his girlfriend to stay over. I had learned about one way from Ieke, which appealed to me. Ieke, our Dutch aupair girl, had told me about the way her mother dealt with her three teenager children's requests to have someone stay over. Each child had his/her own bedroom with a single bed. The guest room had a double bed. If one of the children wanted a boyfriend or girlfriend to stay over, they had to request the guest room for either Friday or Saturday night beforehand, i.e. no bringing

home someone unannounced. And the following morning they had to be at the breakfast table with their boyfriend or girlfriend for family breakfast. Ieke said that this had a very strong dissuasive factor. Jean-Luc and I had often laughed about this idea, and I asked him to support me implementing it. I wanted to be permissive, but I also wanted to be respected.

E-mail from my sister on January 12, 2002:

The advice I got from our family therapist when I said that I couldn't possibly leave the kids and go to Switzerland and Germany last spring with Steve was to find someone at school, like a young teaching assistant (24) to come and stay with the kids, it is expensive, \$50 a day or more but it is worth it. No strings attached, no paybacks and we feel confident that the kids are in safe hands. Maybe that is a way to go and Jean-Luc must understand that this is the cost of being with a family... just as Steve had to. The payback for him was that we had a wonderful time the last time...

Extracts from my e-mail to John on 14.01.2002 in lower case and his response on 17.01.2002 in upper case:

I have changed dates for going away because I have to find someone to come and live in during the time. So we have booked to go away on February 2, returning February 10. Then I will take the following week off to go skiing with Beatrix at the chalet.

So if you were available for them on the weekends of February 2

I WILL BE IN USA AND CHINA ON THAT WEEK END RETURNING SAT 9th BUT NO PROBLEM IN THEM COMING TO MORLON EVEN IF I AM NOT THERE

and February 9, that would be really appreciated.

Thank you for your support the other evening. I have had such a hard time with this stupid, stupid situation.

I THINK IT IS WONDERFUL THAT WE CAN SUPPORT EACH OTHER; OH WHAT MATURITY DOES:

Edward says that Frédérique is really super! Wonder what you will think of Alex?

FOR THE KIDS FRÉDÉRIQUE IS WONDERFUL.

E-mail from Carmel dated January 15, 2002:

My name is Carmel I. I'm a friend of Brigitte F. She sent me your request looking for someone to look after your teenage children while you are away. I am interested and would like to talk to you further. A little about myself. I am studying psychology specialising in vocational counselling at Université de Lausanne, in the third year of a four year degree. I have both Australian and Swiss nationalities. I am 39 years old, single, live in Versoix and have my own car. My telephone number is It isn't easy to catch me at home so if I am not there please leave a message and I will call you back. Looking forward to hearing from you. Regards, Carmel

On the e-mail print-out I have written: *Paid 820.- for 8 days*

Entry in my work diary on January 16, 2002 :

14:00 Meeting with Mrs. H. (social assistant) and Bea at the SMP (Service Médico-Pédagogique – Medical-Pedagogical Service)

Entry in my work diary on January 21, 2002:

18:30 Meeting with Carmel at home

Entry in my work diary on January 25, 2002:

Meeting with M. R., Mrs.H. and Edward at the Atelier-Classe (Learning institution)

Document “Convention of placement” dated January 25, 2002, translated from French. The convention has the letter head of the Canton of Geneva, Department of Public Instruction, Office of Youth, Medical-Pedagogical Services (SMP). It is a legal agreement between the legal representatives of the child, the director of the Workshop-Class, and the social assistant and representative of the SMP that Edward will start on February 19, 2002, as a student. It also mentions that Edward is the beneficiary of the invalidity assurance (Assurance Invalidité, or AI, as it is called in Switzerland.)

The convention has an attachment, called the “Engagement”, by which I commit to paying 8.- francs a day for his meals. This stipulates that I am legally bound to pay this amount, and is also an acknowledgement of the laws that I will break should I not pay, and the resulting procedure.

FOJ Brochure (translated from French):

The Workshop-Class of the Official Foundation of Youth (FOJ) is a day-school which welcomes 10 young people, boys and girls, between the ages of 15 and 20. These young people have experienced in the family and larger social environments such perturbations that their obligatory schooling was in some way affected. They do not necessarily have serious personality problems but they have put in place various behavioural mechanisms, sometimes very complex, to compensate for their lack of knowledge. In fact, these young people encounter great difficulties in integrating professional and social life.

E-mail from my father dated January 23, 2002 saying thank you for Deborah Tannen's book about family conversations. I had said to him that I thought that we were very critical of each other in our family. He wrote:

I don't recognise the description of our family conversations being negative or personally criticising (apart from once in a while). Yes, in the past, but everyone learns from past mistakes and progresses. I certainly respect my four children (and their spouses), am proud of them and love them. I don't judge them (but did a bit in the past). What I do recognise is that I have more difficulty in understanding conversations with the female members than the male. So these books help in that respect.

I seek to avoid becoming paranoid about my relationships with the family which could come if I am to question "should I say that?" to everything. One needs to retain spontaneity with a bit of directness (that is my personality after all), nicht?

Card from my mother, undated 2002:

Dearest Kate, Thank you for talking to me. I hold all you tell me close to my heart. Please tell me if you'd rather not talk or want to keep it brief. It's OK with me for you to say that. I hope it is a comfort that we will keep, keeping in touch. Have just finished Deborah Tanner. So much I find helpful. Thank you. The title is so true, but can be such a big pit to fall in. Love you lots, Mum and God Bless if it helps.

Entry in my work diary on February 1, 2002 :

10 :00 meeting at the CTJ (Centre thérapeutique du Jour – Day Therapeutic Center)

15:00 meeting with Beatrix and Mrs. H., social assistant, at the SMP

Fax to Beatrix and Edward from Coyaba Beach Resort, Montenegro Bay, Jamaica dated February 4, 2002 (translated from French):

Hello Beatrix and Edward! We have spent our first day in the land of “no woman, no cry”. Yesterday we did nothing besides relaxing and reading in the sun. The hotel is much smaller than the one in Maurice, the beach as well. Yesterday evening in the restaurant there was a black singer singing the songs of Bob Marley. The people here are very friendly. We are enjoying ourselves. We got through the customs in five minutes. Jean-Luc said he would kill me if I dawdled. You can send me a fax too if you want to. The number is below. Say hello to Carmel. Bea, there are lots of cats.

Entry in my diary February 2002:

We have had a week, 9 days vacation in Jamaica and not one fight.

Entry in my work diary on February 11, 2002 :

9:00 meeting with Mrs. H. at the SMP

Page from Edward's diary dated Saturday, February 14, 2002, St. Valentine's Day (translated from French):

*Hi Mum, How are you? I wanted just to offer you these flowers to tell you that I love you and I thank you for everything you do and have done for me. I love you with all my heart. And I am sorry for all the hurt. Love, Edward
PS I will come by for supper if that doesn't bother you.*

Entry in my work diary on February 19, 2002 :

9:00 meeting at the Workshop-Class with Edward for his first day

Postcard from my mother, from South Africa, dated February 20, 2002:

We hope the trip to Jamaica went well and you've now adjusted to the jetlag. The one good thing about coming south is no jet lag. This, I think, is a great holiday destination at the moment. Spent our anniversary in lovely hotel here. Cape Town very interesting. Much love from us both, Mum/Dad, Gran/Granddad, A&C

Entry in my work diary on February 25, 2002 :

19:00 parents meeting at the CTJ

Entry in my work diary on February 26, 2002 :

10:30 meeting with Edward and Dr. H. at the CTJ

Entry in my personal journal on March 4, 2002:

I have sufficient work, but not loads of work. I have registered for the OU course with difficulty. I'm late – I haven't received the books.

I met with Chantal and Gerry and feel depressed cause I don't have much work – and I don't feel like looking for work.

Even Jean-Luc feels this year is different – a paradigm shift. I feel like I'm waiting for something. Something will indicate what I should/could/will be doing. Which direction or what task will I be doing?

Entry in my diary on March 11, 2002, after my session with Evy:

Dream of March 2 was after an argument with Jean-Luc where he behaved like the 'neighbour' of my dream. Jean-Luc, my animus who transformed the house where I lived as a child, into a modern, peaceful house (my psyche) is killed.

Killed by the neighbour, the shadow of the animus (This gets complicated, says Evy). This shadow is everything I hate in men, he is misogynist, piggish, powerful, a lout. He lies with two women auxiliaries who spy on me for him, "les mauvaises langues" (the bad tongues). I'm in danger. Having killed the creative, I find myself with his shadow, the one who scares me with his physical strength. It reminds me of the work I did with that woman near the Parc Geisendorf, when I was so angry. The monster –fish-boat under the surface of the water, ready to strike and maim.

Entry in my work diary on March 15, 2002 :

10:00 meeting with Edward and Dr. H. at the CTJ

Entry in my diary dated March 23, 2002:

I'm getting really uptight with certain people. I feel 'susceptible'. I get really irritated by my father and his stuff about the party. I get cheesed off with Anna from C company who sends me 'the only negative feedback I've heard is ...'.

I'm pissed off / worried about Edward who is lying, stretching the limits. I'm tired at the end of the day. I don't feel creative at all. What's going on?

My dreams are bringing up old boyfriends / old relationships where I am trapped by men. I feel so hemmed in and I'm so angry for being 'put upon'. I

don't want to do what others want me to do. I want to do what I want – which might not be much. But I'm so angry, ready to spit at anyone who pushes me. I want JL to make an effort, but I don't want him to come to London if he doesn't want to. I feel it's more about being angry with him for not giving me a birthday present. It feels like my old anger against men.

Entry in my work diary on March 25, 2002 :

10:30 meeting with Edward and Dr. H. at the CTJ

Entry in my diary dated March 25, 2002, after my session with Evy:

Definitely scared of men, defensive with them. They represent a danger. In real life, I don't give them a chance. Told her about OU statistics course difficulties. She says math is masculine. Coming to terms with math and masculinity. Draw on the 'nice male teacher' who is ready to help me.

Entry in my work diary on March 28, 2002 :

School holidays. Edward goes to Alexandra's from Thursday evening to Monday evening.

Entry in my work diary on March 29, 2002 (Easter Friday):

Departure for London with Beatrix and Sabrina

Entry in my work diary on April 1st, 2002:

Return from London

Entry in my diary dated April 4, 2002:

A tense time with Edward, after a wonderful weekend with Bea and Sabrina without Jean-Luc in London. Edward is so angry and aggressive, not coming home, not going to the CTJ. Am fed up. What to do that is right for him, but for me? I too have to live!

Entry in my work diary on April 4, 2002:

16:00 SMP

17:00 Police

20:00 Edward to Emergency (Hospital)

Bea at John's

Entry in my diary dated April 5, 2002:

Edward was found by the police yesterday and taken by force to Belle-Idée. He left me a message on my answering machine: Salle conne (Dirty bitch). The SMP tells me I'm too responsible. Edward will stay at Belle-Idée until he goes to a foyer. I'm told to look after myself.

Entry in my work diary on April 5, 2002:

10:00 meeting at the SMP

Entry in my diary dated April 6, 2002:

Why is it that I feel so responsible for my children? Why is it that I can't stand the idea of them suffering?

Bea told me yesterday that she feels understood by me, that she feels she can confide in me.

Edward has always confided in me. He has suffered more. And he has not been able to get over his suffering. To have a little boy who has suffered so much has been so hard. It reminds me of that black and white film I once saw where a woman was given a baby who didn't stop crying – and she went crazy. Do I want to control everything? I don't think so, but I did want to make my kids happy even if somehow I knew that childhood is no rose garden.

But Edward's sufferings are his own fabrication. Not that they are not real, but they are his interpretations according to his perceptions, not mine. I'm not the mother he needs now, cause I cannot be the military boot camp sergeant. I cannot impose limitations, limits, boundaries and enforce them. I can no longer listen to his sufferings which he uses to manipulate me – to make me feel sorry, to give in, to loosen the rules.

To be so close to someone that you don't see yourselves separately, you only see the other by the links. We are wife/husband. We are mother/son. It happens to me in other relationships that I hitch on to others (Fiona, Vero) and I cannot see them for what they are. I cannot describe them. I only know how I feel when I am with them cause together we seem to be complete.

Contrary to Edward, I don't seem to have pure intuition about people, although I am an intuitive. It is like my radars are damaged – and I pick up the wrong signals and act as if they were good. I think that a lot has to do with my childhood. Having a father who didn't love me – and having to act lovingly and respectfully towards him.

Entry in my diary dated April 8, 2002, after a session with Evy:

She points out that even if I have done a mistake, it is not so bad. I can pick up from where I am. I don't have to repair or do the extra time and finish. I'm forgiving myself. I'm not blaming myself.

Entry in my work diary on April 9, 2002:

Edward transferred to the UCA.

Entry in my work diary on April 11, 2002:

Evaluation with Jean-Luc at the Workshop-Class cancelled

Entry in my work diary on April 15, 2002:

Parents' meeting at the CTJ

Entry in my diary dated April 16, 2002:

Last night Jean-Luc listened to me a bit about the support group at the Centre T du jour. He starts criticizing what the doctor said. I told him that what was great is that you are allowed to say what you feel and that it is accepted that what someone else feels is different, but it is real.

He told me that he was fed-up with all the 'molly-coddling'. I told him that one woman said that it was so hard to understand another person's suffering. She said one person could be unemployed and that will be ok, but another person will suffer terribly. She said at another point that the person who is suffering does not always realize what she is doing to the others, or can't stop herself. I see what Charlotte means when she says I'm doing it all on my own.

There is part of me who is so practical, so hard-working, conscientious, perfectionist, who goes unrecognized, who is made to feel useless, worthless. It's been a tough day – all of this weighing on my mind during my course. A message from John saying Edward can go live at Morlon with Granny Betty. A call from Edward to say he does not want to go and live in a foyer. He wants to come home, go to the Atelier-Classe and find an apprenticeship. Tears, tears, tears. It's so hard to go through all of this.

Entry in my diary dated April 17, 2002:

The evenings are difficult. I have a headache and I want to cry. I want to curl up and die.

Always take a little bit more. And all Jean-Luc can do is remain reserved (scared?) and say 'you must not have him back'. And if he has to come back?

Entry in my work diary on April 18, 2002:
9:00 a.m. Edward's appointment with Dr. S.

Entry in my work diary on April 23, 2002:
11:00 meeting with Mrs. H. at the SMP

List made on May 11, 2002:

<i>Day</i>	<i>Date</i>	<i>Event</i>	<i>Pocket money / fines</i>
<i>Monday</i>	<i>01.04.</i>	<i>Edward comes home, demands money, doesn't return at night</i>	
<i>Tuesday</i>	<i>02.04.</i>	<i>Comes home at 22:30, makes supper, burns food. Comes dressed in a bra into my room at midnight.</i>	
<i>Wednesday</i>	<i>03.04.</i>	<i>Edward doesn't come home at night.</i>	
<i>Thursday</i>	<i>04.04.</i>	<i>Tell him at 10:00 that we are seeing the SMP psy and Mme H. at 16:00. He doesn't come. Recherche actif. Taken to Belle-Idée. Hospitalisation, sortie s/foyer.</i>	
<i>Tuesday</i>	<i>09.04.</i>	<i>Transferred to Unité de Crise pour Adolescents</i>	
<i>Wednesday</i>	<i>17.04.</i>	<i>Meeting Madame Bourdin, social assistant</i>	
<i>Thursday</i>	<i>18.04.</i>	<i>Appointment with Dr. S.</i>	
<i>Friday</i>	<i>20.04.</i>	<i>Edward runs away from UCA cause of Alex. Stays away 2 nights. Returns because JL sends text msg.</i>	
<i>Monday</i>	<i>22.04.</i>	<i>Edward returns home.</i>	
<i>Tuesday</i>	<i>23.04.</i>	<i>Meeting with Madame H.. Ed agrees that he will think about foyer. Doesn't empty the ashtray even after I remind him.</i>	-
<i>Wednesday</i>	<i>24.04.</i>	<i>Left the CTJ. Didn't go to Berthe's for his session. Received 5.- pocket money</i>	- 10.- - 5.-
<i>Thursday</i>	<i>25.04.</i>	<i>Said he would go to the CTJ but didn't go.</i>	- 10.-
<i>Friday</i>	<i>26.04.</i>	<i>Took Edward to the CTJ, went to buy him shoes. Picked him up at 16:30. Matt (my brother) comes over for weekend. Edward stays out all night.</i>	
<i>Saturday</i>	<i>27.04.</i>	<i>Called Edward at 9:00 and 11:00 and asked him to come home. Has fit because his skates are confiscated. Given 2mg</i>	- 5.-

		<i>Risperdal. Sleeps 5 hours. Comes out to dinner. Received pocket money.</i>	
<i>Sunday</i>	<i>28.04.</i>	<i>Gave Edward his rollerskates. He came home for lunch. Matt left. Sylvie, our neighbor, in tears because 600 euros are missing. She and her husband accuse Edward of stealing the money.</i>	
<i>Monday</i>	<i>29.04.</i>	<i>With Jean-Luc we find proof (an exchange receipt from the local exchange office) that he stole 200£ on 12.03. from Sylvie. 15:00 meeting with Dr. H. to confront him with the theft. 16:00 session with Berthe Asked our neighbours to file a complaint of theft with the police.</i>	
<i>Tuesday</i>	<i>30.04.</i>	<i>11:00 Meeting with Madame H.. Says everything is fine. I demand a placement for Edward in a foyer. He leaves angrily. Migraine in the evening</i>	
<i>Wednesday</i>	<i>01.05.</i>	<i>Edward comes home an hour late. I protect him. JL gets furious with me.</i>	
<i>Thursday</i>	<i>02.05.</i>	<i>I start crying in the morning. Take Edward to Doctor S. for his 9:00 appointment, but don't go in. Call Dr. Canavese and ask to be hospitalized. I am hospitalized in the late afternoon in the 2JC, a small psychiatric unit in the main hospital. Call Dr. H..</i>	
<i>Friday</i>	<i>03.05.</i>	<i>Edward is placed at the Foyer du Pont. Goes to Atelier-Classe. Runs away. JL visits me.</i>	
<i>Saturday</i>	<i>04.05.</i>	<i>Get message that he has run away. Call him to ask him to return. He does. JL comes for meeting with Dr. Rubowsky. I get sent home.</i>	
<i>Sunday</i>	<i>05.05.</i>	<i>Edward runs away from foyer.</i>	

<i>Tuesday</i>	<i>07.05.</i>	<i>Gerald tells me Edward may be kicked out of the CTJ.</i>	
<i>Wednesday</i>	<i>08.05.</i>	<i>Meeting at foyer for Edward and Dr. H.. Edward doesn't go. File a missing person report with the police who undertake an active search for him.</i>	
<i>Thursday</i>	<i>09.05.</i>	<i>Edward hospitalized at 2JC.</i>	
<i>Saturday</i>	<i>11.05.</i>	<i>We visit Edward. He has a fit. Nurse tells us of HUG Belle-Idée's Service de développement mental. Told not to visit again until Monday.</i>	

Medical report from Dr. S., endocrinologist, to Dr. J-C. C. , the family doctor, dated May 02, 2002, translated from French:

Re: Edward, born 17.12.1984 Consultations of April 18 and May 2, 2002

Dear colleague,

I have seen Edward, whom you know well, for a check-up of his treatment, and who started a treatment with Androderm (one patch per day, applied in the evening).

He is still in treatment with Dr. H. of the Adolescent Crisis Unit. He has had a five-day stay in the psychiatric hospital Belle-Idée during the month of April. He is taking 1 mg of Risperdal each day. He should start school in one week's time.

He has a sprained wrist from a fall when roller-skating. He has often a small skin outbreak where he applies his patch, for which he should use a cream like Betnovate.

The clinical examination shows that the boy measures 186,3 cm at the age of 17 years and 4 months. He has grown 0.8 since November. His height is +2SD. His weight is 62,5 kg (he has lost 4 kg). His weight is -1SD for his height. The examination shows that in general he is in good health. He has still this lanky look. His face has a beardless presentation. The skin is without acne. His heart and lung auscultation is normal. His pulse is at 64/min and the blood pressure at 108/60 mmHg. His abdomen is supple and without pain. The liver and spleen present no anomalies. The kidney is supple.

Concerning his puberty, there is more underarm (A2 level) and pubic (PP3) hair growth. His testicles measure and his penis There is a slight gynecomasty. The thyroid is normal. The teeth are in order. He still has orthodontic treatment.

In total, we can note a small progression in his puberty.

Edward is particularly embarrassed that he does not shave. However, he has had sexual relations which went well.

The endocrinological evaluation shows that the testosterone has normalized at 12nmol/l. Normal values are situated between 10 and 22. The FSH remains high at 43 U/l. The same goes for the LH which is at 21,4 U/l.

Seeing that the puberty development is not complete, in particular the hair growth remains insufficient for an adult man and that he does not need to shave, we had envisaged the possibility of using two Androderm patches per day. It would not bother him.

However, seeing that the testosterone value is in the normal range, and that I do not wish to give him more testosterone because of his basic illness, I have decided to stay with the same treatment, i.e. one Androderm patch per day. He is embarrassed by the fact that he does not need to shave, but I believe that Edward has understood the problem. Furthermore, putting a patch on twice a day could be tedious for him. We therefore remain with the same treatment.

I would like to see Edward in six months.

Geneva University Hospital

Summary of stay

Name and first name: Lindley, Katherine

Date of birth: 17.07.1957

Date of admission: 02.05.2002

Date of exit: 04.05.2002

Date of report: 04.05.2002

Division : Medical-Surgical Emergency – Unit 2-JC

Diagnostic code: CIM 10

Principal diagnostic: Major depressive episode, current average F32.1

Other diagnostic: None

Admission conditions:

Voluntary entry voucher, established by Dr. I W., on 02.05.02.

Entry done by Dr. R.

Anamnesis elements:

Female patient, English nationality, divorced, mother of a 17 year old son and a 15 year old daughter. Her son suffers from Klinefelter syndrome with frequent behavioural problems. He is in the care of the SMP (Service medico-pédagogique). His behaviour has deteriorated in the past few days. Aggressivity increase. The patient is exhausted, having suicidal thoughts. She is treated by Dr. J.-C. C. who has sent her to this unit.

Status upon departure on 04.05.02

Patient calm and collaborative

Oriented "T/E"

Sad. No suicidal ideas, nor psychotic symptoms.

Discussion and evolution:

Patient has evolved favorably, under treatment of Zyprexa and Stilnox.

We have discussed the project of finding an association to allow the patient to find solutions concerning her son, and propose that she places her son under legal guardianship. She can no longer take responsibility for his violence and social situation. We will talk to Dr. H. of the SMP.

Exit conditions:

Should take up psychoanalysis

Proposition to place her son under legal guardianship

Proposition to contact the association "Le Relais".

Complementary examinations:

None

Treatment after exit:

None

E-mail from my sister-in-law, Sue, dated May 8, 2002:

Thanks for the attached I hope you are proud of yourself making me quietly cry at work with the attachment. I've just passed it onto someone I think will appreciate it.

*How are you doing? Matt let me see your e mail yesterday and I am really feeling for you. I hope this time apart from Edward allows you to re-charge a bit I can't really begin to imagine how you are feeling but we support you in whatever you choose to do. I admire your strength and ability to keep going.
Love, Sue*

-----Original Message-----

From: Kate Lindley Sent: 08 May 2002 09:59 Subject: Mothers

From one mother to another. If you send this to just one person, it should make it all the way around by Mother's Day.

This is for all the mothers who have sat up all night with sick toddlers in their arms, wiping up barf laced with Kraft dinner and wieners, birthday cake, and cherry Kool-Aid saying, "It's OK honey, Mommy's here."

Who have walked around the house all night with their babies when they kept crying and wouldn't stop.

This is for all the mothers who have shown up at work with spit-up in their hair and milk stains on their blouses and diapers in their purse.

For all the mothers who have run carpools and made dozens of cookies for school teas and sewn Halloween costumes. And all the mothers who HAVEN'T because they're at work trying to keep on top of the bills.

This is for the mothers who gave birth to babies they'll never see. And the mothers who took those babies and gave them homes and all their love.

This is for all the mothers who have frozen their buns off on metal bleachers at hockey, baseball or soccer games any night of the week instead of watching from their cars, so that when their kids asked, "Did you see me?" they could say, "Of course, I wouldn't have missed it for the world," and meant it.

This is for all the mothers who have yelled at their kids in the grocery store and swatted them in despair when they stomped their feet like a tired 2-year old does, who wants ice cream before dinner, and then hated themselves for "losing" it.

This is for all the mothers who sat down with their children and explained all about making babies. And for all the mothers who wanted to but just couldn't.

For all the mothers who read "Goodnight, Moon" twice a night for a year. And then read it again. "Just one more time."

This is for all the mothers who taught their children to tie their shoelaces before they started school. And for all the mothers who opted for Velcro instead.

This is for all the mothers who taught their sons to cook and sew and their daughters to be brave and strong (and sink a jump shot.)

This is for all mothers whose heads turn automatically when a little voice calls "Mom?" in a crowd, even though they know their own offspring are at home.

This is for all the mothers who sent their kids to school with stomach aches, assuring them they'd be just FINE once they got there, only to get calls from the school nurse an hour later asking them to please pick them up. Right away. And they do.

This is for mothers whose children have gone astray, and who can't find the words to reach them.

For all the mothers who bite their lips sometimes until they bleed - when their 14 year olds dye their hair green.

What makes a good Mother anyway? Is it patience? Compassion? Broad hips? The ability to nurse a baby, cook dinner, and sew a button on a shirt, all at the same time? Or is it the heart? Is it the ache you feel when you watch your son or daughter disappear down the St., walking to school alone for the very first time? Or the terror in your heart at 1 AM when your teenager with the new driver's license is an hour late getting home. The jolt that takes you from sleep to dread, from bed to crib at 2

A.M. to put your hand on the back of a sleeping baby? Or to feel the dull ache as you look in on your sleeping daughter or son the night before they leave for a college in another city?

The need to flee from wherever you are and hug your child when you hear news of a fire, a car accident, a child dying?

For all the mothers of the victims of all the school shootings, and the mothers of those who did the shooting. For the mothers of the survivors, and the mothers who sat in front of their TVs in horror, hugging their child who just came home from school, safely.

This is for mothers who have tearfully placed flowers and teddy bears on their children's graves. Whose children have died from illness, accidents and the worst of all and hardest to comprehend, suicides.

This is for young mothers stumbling through diaper changes and sleep deprivation. And mature mothers who have learned and are still learning, to let go.

For working mothers and stay-at-home mothers. Single mothers and married mothers.

Grandmothers whose wisdom and love remains a constant for their grown children and their children's children.

For Mothers with money, and Mothers without.

This is for you all. So hang in there.

Please pass this along to all the Moms in your life.

"Home is what catches you when you fall - and we all fall."

Please pass this to a wonderful mother you know.

Entry in my diary dated May 11, 2002:

*Don't criticize me
You listen to me
Your eyes open wide
Horrified.*

*Oh, God, it's so awful.
Why did this happen to me?
What did I do to deserve this?*

*That's what you think too.
But you try so hard
You put on a brave face.
Oh, please say something
To ease my pain
Tell me it will be all right again
He'll get better soon.
But you can't.
Cause you don't know your arse from your elbow
You haven't a clue except for what you've read in women's magazines.
The doctor's opinion is a list of ticked statements.
I've heard them before.
Freudian psychoanalytic theory
Would I agree if I could understand?*

*Have compassion for those who fear mental illness
But expect none from them
Don't tell them even when they ask
They really would prefer not to know.*

Entry in my work diary on May 14, 2002:

Edward goes to his father's house in Morlon.

E-mail to John on May 16, 2002:

Personal re Edward

Hi, Hope all is well. Two things:

*1. Edward is Swiss since May 7th and needs to go to the Service des passeports
(Passport service) to get his carte d'identité (I.D. card) the next time he is in*

Geneva. I am going to send you a copy of the arrêté just in case your local friendly *contrôle de l'habitant* (the Swiss office of inhabitant control) shows up and wants to register him in Morlon. He still has in his possession his C permit (the Swiss equivalent of a green card, residence permit) which has a letter saying that it is extended to May 31. He will have to return this to the *Service des passeports* (Passport service) He will need various papers plus 35.- which I will give him or get to him when he comes. He needs to take two recent passport photos with him (frontal, without hat). Gerard, the *infirmier référent*, (the nurse in charge of Edward at the CTJ) told me that there should be a 'bilan' (evaluation) with you and Edward at the *Centre du Jour* next week so please include enough time (an hour) for him to go to the *Service des passeports* which is open from 9:00 - 15:30. Less waiting times in mornings.

2. I received on Tuesday in the post a convocation for Edward to appear yesterday at the local police station to confront Sylvie and René (our neighbours) about the theft of 200£ in March (for which we have proof he did it) and 600 euros (for which he is suspected). Because he was leaving for Morlon, the police agreed to put it off until he returns to Geneva. Sylvie made her deposition yesterday but it will not go to the *Parquet* if there is a confrontation with the outcome of him promising to pay back with dates and so on. He could be jailed if it goes to *Tribunal des Enfants*. Sylvie does not want that to happen.
That's it.

E-mail from John in reply to my e-mail dated May 16, 2002:
I tried to call you but no answer on mobile or at home. All is well (famous last words). Can you give me the number of the CdJ and more particularly "Gérard". Does Gérard coordinate with Dr. H. (or whatever his real name is)? Is the Swiss thing urgent or can it wait until June?
Would it not be better (from various points of view) to get Edward to the Police next week? If yes who do I contact for an appointment?
Hope you are Ok.

Entry in my diary dated May 18, 2002:
Edward has gone to John's since Tuesday. John has got him a job for a couple of weeks. Mrs. H. comes back from holiday on Tuesday so we can start looking for a foyer. John says he would prefer him (Edward) to stay with him rather than live in a foyer.

It is raining – after a couple of days of beautiful weather – on Saturday. My body is tired. I should look after myself.

I feel alert and anxious about Edward. If he decides he wants to come back, will he reappear? If his father can't take it anymore, will he send him back?

I feel I'm behaving like his father has behaved. I don't want to know.

Débrouillez-vous, ce n'est pas mon problème! (Sort it out, it's not my problem !)

E-mail to my family dated May 21, 2002:

Subject: A bit of good news

I have just had my son on the phone. He went to work in the kitchens today and made club sandwiches and banana splits. And he said he enjoyed it. He also said that he can't quite get over the fact that his Dad has taken him on seeing that he never had any time for him. (They did have a tough weekend – Edward ran away for the night to spend it with Alex.) He has to come to Geneva next Monday to check in for military service. He won't have been Swiss for three weeks (he still doesn't have a passport) and they already want him to sign up. I know he is not likely to be accepted. So it looks like they have survived their first week together. Love, Kate

Entry in my work diary on May 20, 2002:

Concert Jean-Jacques Goldman

E-mail to John dated May 23, 2002:

Just wanted to give you the times for Edward:

Recensement militaire: quai Ernest-Ansermet 18bis entre 7h30 et 15h00

*Carte d'identité: Service des passeports, Rue Henri-Fazy 2, entre 9h00 et 15h30
- it is better to go in the morning, otherwise from 11:30 onwards there is about an hour and a half wait.*

Police? Do you want to call Sylvie and see if she can fix that confrontation?

Centre du Jour: Gerald will call you today about seeing you and/or Edward.

I have my therapy session from 8:30 to 9:30. And then I start a workshop at 12:30 so I could take him to the Service des Passeports at 10:00. It would be good to do that before he goes to the Recensement militaire. Tell me when he arrives so I can give him or get to him all the papers he needs.

Reply from John dated May 23, 2002:

hi from Paris, I am in Azerbaijan on Monday, Frederique has suggested he stays with her in Lausanne (she has a spare room for au pair not there) on Sunday night and she will put him on the train for Geneva on Monday morning. He is worried about the Military thing (normal, I was also). If Gerard could meet him and help him it would be great. I am back in Switzerland tonight late and all day tomorrow, let's talk. John

Entry in my diary dated May 25, 2002:

Went to see the Vagina Monologues with Bea, Sylvie and Julie. I remember Bea and Julie fell asleep to the relief of Sylvie and myself.

Entry in my work diary on May 29, 2002:

16:00 appointment with Mrs. H.

Entry in my diary on June 2, 2002:

I move along, but I get laid low by practicalities, by responsibility of Edward. I am so scared of having to admit this boy to an institution, so scared that he really is mentally ill.

Entry in my work diary on June 4, 2002:

16:00 appointment with Berthe

E-mail to John dated June 5, 2002:

I just wanted to update you before you see the SMP gang. I walked out with a list of actions from the meeting with Madame H., the social assistant. The SMP, i.e. Dr. H., recommends that Edward is put in an institution, i.e. l'Institut Maïeutique in Lausanne. I have requested the documentation. I have talked to the Service du développement mental, Dr. B. who says that they have only treated Klinefelter boys when they also had an IQ of under 70. She said that they usually have a 'parcours scolaire problématique' (problematic school path) which results in psychic problems. So sometimes they have seen boys whose IQ is slightly higher than 70, but mainly because of the psychic problems. (She says that we did well in keeping Edward in school for so long.)

Berthe has the AI dossier because I asked the AI to send it to her (cause they cannot or will not send it to the parents, which is actually illegal...). We are going to look at the dossier together tomorrow and then she will give me a copy. The capacity tests were done two years with an unwilling Edward so they

are not quite up to date. But I think they would help us to direct Edward in his 'career'.

The psychologist at the AI who is in charge of Edward's dossier is Madame B., tel. no. 022 8095321. Now there is still an open request from me to the AI (which has not been treated for 18 months because of an incompetent psychologist, Madame L., who never returned calls nor answered letters. I think she has been fired). This request is for "Formation scolaire spéciale" (special educational needs) and Madame B. is the one who will tell us what is possible. If Edward needs to be institutionalised, she will tell us how much the AI will pay towards which place. You need to know that most options will disappear for Edward when he hits 18. The AI may want to do another assessment. Madame B. is on vacation this week and I will talk with her next week.

We also talked of putting Edward under 'tutelle'. Madame H. was horrified, but it is up to the judge to decide when and if we request it. This would mean that Edward would not come of age, and the judgement is hard to reverse. She suggested that Edward could ask to be put under a tutelle temporaire at the age of 18. (Jean-Luc told her at this point that her recommendation was not welcome. He got very, very angry with her and told her that while she and the others sat in their ivory tower from 9 to 5, I was the one whose nerves were being played with and had to go to hospital).

The SMP will not look for another place in a foyer. I do not know if they still harbour the idea that Edward could/should come back to live with me. I don't want to play the violin, but I am still very fragile.

Dr. J.C. C. has prescribed Prozac to me today and told me to keep on working at 50%. Every time there is an upset, I am back to crying fits. So I spent last Thursday in tears after seeing Madame H., and I spent Tuesday and most of today in tears again.

So I think that from the above, our interlocuteurs privilégiés (the people with whom we will work together) will be Madame B.(AI) and Berthe (Edward's psychotherapist) cause she knows him so well. I don't want to exclude Jean-Luc because I think he has the most knowledge of Klinefelters. I agree that you and I meet with Edward to talk about the possibilities, but maybe we could meet with all of the above to discuss beforehand.

I am really grateful to you for taking him on when I can't anymore. I have ordered his patches from Dr. S. and will send them to you. Please check he puts one on each evening. I have also received his Swiss ID card which I will send on.

Reply from John dated June 6, 2002 :

Thanks for all the info. I agree with you about the enlarged meeting attendance it all makes sense. I am sorry I have not been able to help more before so whatever I do know is just my duty . I am doing it very happily and really hope that we can avoid an institution but that is probably an emotional response, we will obviously do what is best for E.

Entry in my work diary on June 11, 2002:

Appointment with Dr. B., psychiatrist, in Versoix.

My doctor, Dr. Canavese, has thought it would be a good idea for me to see a psychiatrist, not to take Prozac without any psychiatric supervision. I remember going to see this doctor and telling him what was happening to me. He showed surprise on several occasions, said it was amazing what I had been through. Many years later, in 2010, I debated the effect of having a psychiatrist or a psychotherapist showing surprise at what I had been through with my sister-in-law, Annie-Laure. I had told her that I was returning to see Evy to have some support while writing this dissertation. She asked me why I wanted to go back to someone who had heard my story before, who would not help me in a different way to move forward, to get over what had happened. I told her I wanted someone who knew what had happened, not someone who sat there and showed surprise, and who would then say how brave and courageous I had been.

Entry in my work diary on June 19, 2002: *Appointment with Dr. B.*

The following appointment on June 24 was cancelled, crossed out in my work diary. There were no subsequent appointments.

Entry in my work diary on July 1, 2002: *3 weeks of NLP training*

Card from Berthe, Edward's psychotherapist dated July 10, 2002, translated from French:

In the enclosed letter, I have expressed what I would like to have said in the meeting of July 18. You can if you so wish use this letter. As I have not been contacted by the SMP, I am sending it to you.

Entry in my diary dated July 11, 2002:

Argument with JL on the phone last night about Edward. I related to him what Ute H. said about using my maternal intuition to do what is right.

I am worried when I hear John say he can't do this and he can't do that, that he hasn't got things organized.

I don't want to sit in a meeting and hear everyone's lethargy and get the responsibility for the next steps.

Ute H. was a psychotherapist recommended to me, who worked with young people who had learning difficulties. I talked to her on the telephone. I remember thinking "what is my maternal intuition, and what is it telling me?" when she told me to use it.

Entry in my diary dated July 17, 2002:

Jean-Luc and John go on July 17 to a SMP meeting with Edward. Without me. They take over. I am released.

Entry in my work diary dated July 22 to July 26, 2002 :

Montréal

Entry in my work diary dated July 27 to August 5, 2002:

UK / Castle Rising

Entry in my work diary dated August 3, 2002:

Parents' 50th wedding anniversary celebration

Entry in my work diary dated August 7 to August 10, 2002:

Charlotte and family

Entry in my work diary dated August 10, 2002:

Bea's party

Entry in my work diary dated August 11, 2002:

Bea leaves for USA

Letter from my father dated August 11, 2002:

Dear Charlotte, Matthew, Mark and Kate,

Some weeks ago I came across the following: Who would be a parent?

You get a front row seat to history to witness all the early stages of another human being. You get to be immortal. You get another branch added to your family tree and, if you're lucky, a long list of limbs in your obituary called grandchildren. You get education in psychology, nursing, criminal justice, communications and human sexuality that no college can match. In fact, having a child is probably the greatest single step you will ever take for your own personal growth.

In the eyes of a child you right up there with God. You have all the power to heal fears, scare away monsters under the bed, patch a broken heart, police a slumber party, ground them forever and love without limits so that one day they will, like you, love without counting the cost.

For me, that say it all. I am still overwhelmed by what you did for us last weekend, humbled by it all and just so grateful to God for his gift to us of the four of you. Thank you from the bottom of my heart and with all my love, Dad. Kate, thanks so much for organizing the "entertainment" so brilliantly and for all you did whilst here, for having such a gorgeous daughter and for showing us so much caring. Only regret is that Edward couldn't come but maybe it was better so we need to see him if we come in September/October.

Entry in my work diary dated August 12, 2002:

Bea in USA, Bea is 16

Entry in my diary dated August 18, 2002 :

Jean-Luc is niggling and criticizing. I have laughed at him saying he's looking for the button. He's found it. Non-stop doing what he wants me to do – I've had it!

Entry in my work diary dated August 19, 2002:

Bea returns from USA

E-mail from John dated August 21, 2002:

Two points one question and one is info:

1) *Would you consider it appropriate if I kept (some or part) of the money for E. It would help me pay the phone and clothe him. Thanks for your comments.*

2) *Things are OK for the moment, he looked after Granny B rather well, the house was in a relatively good state on my return (he made an obvious effort). Frédérique thinks he stole (100Sfr) from her but he swears he did not (so the story goes on). On the job/apprenticeship front he is waiting for the offices to open next week. My feeling is that he has calmed down and that things are sinking in, we had a lot of talking, he was angry against me (the world is angry with me so that does not change things a lot). For the moment I think the best is to carry on with the strategy of letting him take charge, I will continue to monitor things closely and have adjusted my travel plans to reduce the amount of time away this coming fall.*

E-mail reply to John dated August 21, 2002:

Re 2) oh the joys of parenthood. Having angry kids... I was quite amazed watching Charlotte and Steve and their three kids. They are very attentive and caring parents, and their kids "never say a thank-you". They don't set the table, they don't clear away, they drop their clothes on the floor at the end of the day and ask the next day "where is my bra, mother?". At one point they started criticising Charlotte in front of me, and I told them that they could stop right then and there, that my kids don't have parents who do so much for them - and to hear them criticise their mother was too much for me. They could do that elsewhere, preferably not at all.

Re 1) You will have to allow me a little more time thinking about this. I obviously am very grateful that you have taken him on more from a "relationship" point of view, than from a financial point of view. I also know what it is like to pay 480.- a month for his telephone calls. I told Edward that the consequences of his behaviour (the phone being cut off) had really scared his grandmother and made her angry - and I hope he bore the responsibility of looking after her well!!

As a teacher of negotiation skills, (and avid believer in Getting To Yes) I would like to think about the "objective criteria" against which we would evaluate an agreement.

If we looked at Edward's situation from a legal point of view (parental authority and so on) we are legally obliged to stick to the divorce ruling. Consulting the judge means taking a lawyer and it costs between 8'000.- and 10'000.- (I know

because I wanted at one point to have the amount you paid for their keep adjusted to your salary - around the time you wrote to the Service Protection Jeunesse). Going outside that divorce ruling means that we have to be really clear and committed to what we are doing, because at any point you can return Edward to me and I have to accept him. However by going the legal way, we could change the parental authority, or we could get joint parental authority because that is granted since 2000 I think.

At the same time, we could evaluate the financial situation and reassess/adjust the financial provisions made for Edward and Beatrix. Both of our salaries have changed and then again it would be a third party who would decide "competently" on the matter of how much gets paid and by whom. Maybe that would be preferable because under Swiss law we are bound to support our children financially until the age of 25 if they are "en formation". So any new agreement we would make could take into account both of them - for the next nine years!

E-mail reply from John dated August 22, 2002:

I am sorry this has taken such proportions, I was seeing this a simple transaction where you would, kind of, give him money to support his keep while he was with me. If you feel this cannot be done for xyz reasons do not worry, let's keep it simple.

*Concerning money in a more broad sense, I spent 7 years with Clivaz at 12*5.5 and had to go several times cap in hand asking for an extra few thousand to finish a year. I am making a point returning this money but you need to know that I have and will always do my best for the kids. I have sold the boat because I could not cover the payments and need to tighten the budget because of Betty. These were the reasons.*

Entry in my work diary dated August 23, 2002:

Call Mrs. P., psychotherapist, at the SMP

E-mail from John to Jean-Luc and me dated August 27, 2002, telling us that Edward had run away:

New evidence helps us further understand the sexual behaviour of Parrots. Research in this field is still in its infancy and systematic approaches difficult to operationalize. This research has therefore concentrated on long term patient

observation. Early results collected through a small sample of empirical observations encourage us to believe that there is some link between sexual drive and migratory patterns. Parrots, or at least the observed species seem to move towards birds that move from Tahitian islands towards the Alps and meet in lake shore towns.

Unfortunately our research department did not have time to tag the specimen and we are out of contact since a couple of days. For the purpose of this study and its interesting research potential and for the good of the individual we would appreciate the collaboration of our fellow researchers should they come across any evidence, or traces of the specimen.

Letter from my mother dated August 31, 2002:

My dearest Kate and Bea, It has taken four weeks to get down to letter writing, a letter that has been developing in my thoughts, how to say thank you with all my love and gratitude for your love and caring and working so well to brings together four weeks ago today. The celebrations started for me with Bea's visit. It was such a good time – a new experience to share time, not just a grandchild, but with a friend as well. Thank you, Bea. Kate, a great deal of time and effort went into "this is your life" and if we were stunned to silence, let this now be my speech of appreciation. You and Matt 'handled' the event – your presentation together – your skills and confidence were a pleasure to observe and made the event much fun for me and the others. I felt so proud. To have your four together was good, rather special and I am aware of the emotional stress and tensions that lay underneath and so all the more appreciation and love and hope that in our celebration more healing may come. As you too well know, healing wishes of a Mother are very dear, which brings me to Edward who, I was very conscious, was not with us and truly understand all the deep reasons for things to be as they were.

During the party Joan (my mother's older sister) put her hand on mine and pointing to you and Frances (Joan's daughter, my cousin) talking together she said to me, "Aren't we lucky to have such lovely daughters?" and so we are, more than lucky, blessed. Dad showed me the letter he sent you. I endorse all it said – so much more complete and eloquent – but I wanted, 'needed' to say my thanks too from me. My deepest love and thanks. God Bless you all. Love you lots, Mum and Gran

Entry in my work diary dated September 23, 2002:

16:45 Appointment with Mrs. P., Bea's psychotherapist, at the SMP

E-mail to John dated October 7, 2002:

1. Edward has an appointment with Dr. S. on October 31 at 9:30.

2. Edward wants to go and see a dentist and should go, but he also needs to go and have his tracks removed by Dr. P. I told him he could do it during the two weeks he spent in Geneva but he didn't.

3. He got caught by the TPG controllers on a tram or bus without a ticket. There is a fine which increases every three-five days if it is not paid. I told him that I would not pay his 150.- clothes allowance until it was paid, or I would give you the money to pay it, or I would pay it when I receive the fine. Last time I got the fine for him, it cost 90.-. Let me know.

4. I am starting to clear out Edward's room so that it can be used as a guest room. Do you want the train track and trains? There are a whole lot of PC attachments too. I don't have room for all this stuff in my cellar.

This most probably reflects the total uselessness that I feel around our son. I was upset that you did not let me know that you were leaving for travels, and what you had agreed with him. I had two weeks of total anguish knowing that he was hanging about, and there was nothing I could do. The cherry on the cake was Alex's father, Mr. L., whose idea of limits is the same as one of my customers who is in the aeronautic industry : The sky. As JL pointed out, Edward is learning how to survive. So am I, Kate

E-mail reply from John dated October 7, 2002:

I talked to JL this morning and read your mail this evening. You feel useless, so do I. I am at miss about what to do next. JL and I had a talk about this, I wanted to protect you from the shit. Our son is a liar and a rather nasty person when it comes to stealing and being deceitful. However the good news is that I really do not think he is stupid at all, the only problem is that he does not use it in the right way.

You have tried, I have tried and there is little result, just an endless stream of negative behaviours, lack of respect and total selfishness. I will have no remorse in kicking him out in December. I even might press charges against him if he goes on. Obviously my heart is broken and this situation is really playing on my nerves. Nobody wants a son like that let alone while trying to

survive in corporate boardroom warfare. But this is our lot and we have to cope.

Please do not be angry, I prepared my travel, we talked a lot together, he had tasks and addresses for jobs. He even made me believe he was working on things while I was away. What was my disappointment when I came back and found out that he had left, leaving the house wide open (one key is missing) and that I got an earful from Mr L. (sky, no he is an astronaut, he is above the clouds on some other planet). The boy lied to me about everything and takes me for an idiot. The only thing he wants is to be with his girlfriend, spending money he does not have to work for.

I believe that neither you nor I have any more control over him, he has chosen his way and needs to follow his path whatever it leads him towards. Are we surrendering, yes, is it wrong no, have we failed maybe. But the reality is that he does not want us to run his life and he does not realize what he is doing is leading him into an impasse. Words have no more effect, he needs to crash, let us pray he survives.

Entry in my diary dated October 9, 2002:

Reality. Edward is with Alex. They've run away together. Crans?

Edward has run off with Alex. John is leaving today and will be back on Sunday. Edward won't come near me. He won't accept the rules of the house. He and Alex seem to defy everyone. They count on her mother to let them do what they want. There seems to be no masculine energy to put limits on them, to impose rules and some form of framework.

I am worried. So is Jean-Luc, so is John, but we're also angry with Edward. He tells lies. He will be 18 soon, and what will happen? How can we exert effort on Edward who seems to be like a fish, an eel, and who slips away in the night. There is hope, I hope.

Entry in my diary dated October 26, 2002:

Edward was removed by the police from Alex's bedroom last night. I don't know where he spent the night cause JL took over talking to the police. He said that neither I nor he would go and get Edward. The police said they would call a doctor to see if Edward needed to go to the psychiatric ward.

I woke up this morning – and slept on and off for a while. I had fallen asleep when I heard the words 'he's dead'.

Entry in my diary dated October 29, 2002:

Edward spent the night in prison. The police (Brigade des mineurs) say I have to take him back tomorrow morning, i.e. this morning.

What to do? Dr. R., my gynaecologist, says that the results of my blood test show that I'm suffering from nervous tension, anguish, because of long term problems, that I'm masking a depression.

Entry in my diary dated November 4, 2002:

Edward came home on Tuesday, October 29. I had a migraine on Friday, November 1.

E-mail from Jean-Luc dated November 6, 2002, at 16 :38

Subject: La Clairière (Prison for minors) They have asked that you bring his patches and cigarettes. They are open until 22:00 or tomorrow. They recommend that you give cigarettes because the deprivation of freedom is in itself already very difficult, and in any case they limit the consumption to 3 or 4 per day.

E-mail from Jean-Luc to Alec, our lawyer and friend, dated November 7, 2002 at 11:36 (translated from French):

Subject: Edward

Good day, President of the Bar,

Here are some silly and urgent questions. My speciality is in commercial law rather than penal law. The young Edward has been placed in the minors' prison by order of the judge, J-L.R. He has been there since Tuesday. The motive is breaking in, and the complaint was filed by his girlfriend's father, who didn't want to see him in his apartment any more, but ... of course, young Juliette continued to open the door to Romeo. Personally I find it difficult to see breaking in, seeing that the young lady consented. But I repeat I am not knowledgeable about penal law.

It is certainly good that he reflects a bit on the consequences of his actions, but it is surprising that the detention has prolonged. The judge does not wish to liberate him until Juliette has been sent to a boarding school in England. It seems almost arbitrary. The mother and I think that if he has not been liberated by Tuesday, we will have to intervene. So my questions are very down to earth:

1. Can you?/ Do you want to take it on ? 2. How much?

Reply from Alec to Jean-Luc on November 7, 2002, at 13 :59, forwarded to me:
I will take care of it as of tomorrow if the judge persists. And perhaps in any case if he doesn't persist because even if he is liberated there will be a process. As far as the second question is concerned, a good bottle of claret should be sufficient.

Reply from Jean-Luc to Alec on November 7, 2002, at 14 : , with copy to me :
In addition to the bottle, we will add our eternal gratitude.
To come back to the case: I don't doubt that you will be able to get him out in less than 10 minutes based on some minute detail of procedure. However, it is most likely that he will start again, don't forget that the young man suffers from what could be considered as a willingness disorder. As much as he knows and worries of the consequences of returning to Juliette, he won't be able to stop himself. That is why it is necessary to send Juliette abroad and find a place for the Parrot (one of Edward's nicknames). We have to take care of the goat and protect the cabbage. In any case, I think that it is good to have access to his file, to verify the regularity, independently of whether he is liberated now or later.

Entry in my diary dated November 9, 2002:
Edward has been in jail since Tuesday, November 5.

Entry in my work diary on November 9, 2002:
14:00 Visits allowed at the minors' prison, La Clairière
Telephone numbers for the section of minors' police, the prison and the judge
Mr. R-

I remember standing outside the prison, before going in, crying my eyes out, looking at the high fences and barbed wire.

E-mail from Jean-Luc to Alec dated November 11, 2002, at 11:33, copy to me:

Greetings, grand master! News of the day :

The good judge J-L.R. is in the shit and doesn't know what to do anymore. Mrs. C. Q. (SPJ) is there too and doesn't know what else to do. The judge says that he is ready to liberate Edward as soon as he can be admitted into the UCA (Crisis Unit for Adolescents). Mrs. C.Q. is trying to organise it, and has asked the advice of the psychologist at the prison. The prison psychologist says there is no crisis, I will not make out the admission request,. If the judge thinks Edward has nothing to do here at the prison, he shouldn't have sent him. The judge is saying to himself, oh, oh, oh, I have until Tuesday, 9:00 a.m. to calm things down or the terrible lawyer is going to start shouting that I am outside the law and common sense... Then Mrs. C.Q. says to me: Are you ready to have him home? I will stop off at the prison and bring him home. And during this time we are trying to find out where Juliette is ...

Apart from that, Mrs. C.Q. says that it is up to us to request the guardianship procedure. She will be consulted and will give a favourable recommendation. Does it have to be done in the format of a brief (mémoire) or in a form that is available at the court clerk? Does it pay to be a guardian? He is asking for me to be designated. Talk to you later for new adventures.

Entry in my work diary on November 11, 2002:

20:00 Edward leaves Clairière. Call C. Q. at the Service de la Protection de la Jeunesse (SPJ – Service for Youth Protection)

Entry in my diary dated November 18, 2002 :

Session with Evy. My illusion about Edward is disappearing.

E-mail from Jean-Luc to Alec dated November 20, 2002, at 10:59, copy to me:

Subject : News

First of all, thank you for your admiration. I think I will need it soon! Wednesday morning at 7:30 we went to the infamous L. household to try to recuperate our Romeo. Closed doors, no answer on any of the telephone numbers. So we went directly to the police and made out a notification of disappearance. Kate is at her wits' end, it is excluded that they send him back to us. We told the police to notify the SPJ and the judge J-L.R.

The question is: what can we do so that the judge orders his internment in an institution????

Entry in my diary dated November 22, 2002:

Edward is 'on the run' with an 'avis de recherche'. He called me yesterday to say that he wasn't at Alex's, that he was at a friend's in Lausanne, that he was in Switzerland, that he was ok.

He didn't sound ok at all. I guess he's still at Alex's and that her mother is not at all pleased with calls from the police.

I don't really know if what I am doing is right. But I have run out of options. My legal purpose as a parent is to get my child to the age of adulthood with a professional trade or educational baggage so that he can make his way – and that hasn't been done.

The use of police force and the judge's authority – is this appropriate?

Letter from Berthe, Edward's psychotherapist, dated November 24, 2002, translated from French:

After our last telephone conversation about ten days ago, I was left with an uncomfortable feeling. I had the impression that I expressed myself poorly. So I will try to do it better.

I find that Edward needs supervision, as he says it himself when he is "reasonable" and lucid. You have realized that you cannot give him this supervision in your family setting, because he constantly breaks away. I do not what decision has been made, or is being made now, but my impression is that a "school" (like a sheltered workshop) is not sufficient at this moment in time, and he would need an institutional setting (like Institut Maieutique or La Fontanelle). It is in this sense that I said that the psychotherapy with me cannot be sufficient. BUT I would like to be clear that if Edward is in Geneva and/or when he is in Geneva, my wish would be to continue to accompany him because the relationship that we have built up is important, and should be allowed to remain so. I really am very attached to continuing. It is something that I will write to Edward about. I am also ready to continue the discussions with you, or the other parties, as much as possible.

The AI decision for the psychotherapy with me was until June 2002. If you and Edward wish to continue, you will have to ask Dr. P.-C. of the SMP to prolong the arrangement.

I hope to speak to you soon and send you my best wishes. Berthe

Document dated November 24, 2002:

5 pages about Edward's life and events in preparation for Edward's mise sous tutelle

Extract from a letter from my mother dated November 25, 2002:

Thank for your communications and all the Edward happenings. Quite an experience writing your child's biography – this must have been painful – totting it all up. I haven't been in touch on the phone much recently, I just felt that you might need your space, but please don't doubt that my mother feelings for you are very much there and my grandmother feelings as well for Edward. It's good to hear that you are coping well, so long as you feel it's OK inside. Yes it is fucking awful to have a son with Klinefelters – and hell that it is so difficult when you have done your best doesn't seem to be enough for Edward. It is painful to imagine a child being taken over – is it too much to hope that your maternal love will help E, knowing you're there for him and don't have to do the discipline. P.S. Put on your Hello Dolly record – it used to do you good.

E-mail from Kate to Dr. J-C.C. on November 25, 2002 at 18:25 :

Subject : Edward

The latest news concerning my son is not very positive, and we have decided to request that he be placed under legal guardianship. I have had to write a biography of the young man, and my partner, Jean-Luc, has checked it as well as all the doctors' reports, schools, etc.

Jean-Luc tells me that the report requires a medical report saying that Edward's physical and mental development is retarded because of the Klinefelter syndrome. Could you please do that? Edward stopped applying his patches this summer. He went to see Dr. S. about three weeks ago, and had a blood test. He should have gone back for the results last week and to discuss the continuation of treatment, but he has disappeared since 10 days so I suppose he has not gone. I don't know what to do because I don't know when I will see him again.

If you have any questions, please call Jean-Luc. I will be teaching all day tomorrow. Many thanks and best regards.

E-mail reply from Dr. J-C. C. with copy to Jean-Luc, dated November 26, 2002, at 13:37:

I understand the importance of your procedure and the pain that it must generate, and believe me that I share it. I am unfortunately not able to make a

report about Edward because I am obliged to keep confidentiality. I know that this remark must seem light and futile, but it is inevitable on a legal medical level. Please keep me informed.

E-mail from Jean-Luc to Alec with copy to me, dated November 26, 2002, at 18:34:

The boy has gone to Paris with Mrs. L. (Alex's mother). Judge J-L.R. should order a placement for assessment, based on the report from the SPJ, in view of deprivation of freedom with the aim of assistance. The problem is that he should be at the Fontanelle establishment before December 12, the day they leave for a desert rally.

Is there any way that we can piss that bitch L. (excuse my French) off with a penal complaint for sequestration? Taking a child away from parental authority?

PS You should have received the biography and all the stuff in a large envelope. It is not necessarily clear for a judge. I have asked our doctor for a medical report. We should have it by the end of the week.

Entry in my work diary for the week of November 25-29, 2002:

Telephone numbers of Mrs. L. in Paris, the French police inspector and the customs office in Paris-Bourget.

I had a telephone call at midnight one day that week from the customs officer in Paris-Bourget asking if my son had permission to fly from Paris to Morocco with the L. family. I told the man that he did not have permission, that Mrs. L. did not have permission to take my son out of the country. He gave me the name of a French police inspector to call.

Entry in my diary dated December 2, 2002:

Edward on the phone from Paris shouting at me, telling me that he is going to commit suicide, that he's on the fifth floor, he's opening the window, I hear the noise from the St., Alex shouting 'mon chou' and I hung up.

So how does the story end? It is not a sign of courage or strength to insist in a hopeless struggle.

Entry in my work diary on December 3, 2002:

17:00 Edward arrives from Paris. 18:30 Fontanelle

With Mrs. C.Q. we waited for Edward at the customs office in Geneva. He came through the customs, saw us and pushed past out into the station. We thought that he had run away, but he came back. We took him to Fontanelle home in the canton of Valais by car. We stopped once or twice on the highway for him and Colette to have a smoke. At the Fontanelle home, the man in charge said that he thought Edward was too clever, that he wouldn't accept the discipline and he wouldn't take him on.

E-mail from Jean-Luc to me, dated December 6, 2002:

Subject : New version of the legal brief

32. His father proposes to take him in to his home, near the town of B. He repeatedly runs away to Geneva to be with Alexandra.

In the month of October 2002, while his father is on business travels, Edward leaves his father's house to live with Alexandra in her parent's home. They spend most of their time locked in her room.

33. Edward refuses to leave Alexandra. Her father, Mr. L. asks the police to help him evacuate Edward on Friday, October 25, at about 23:00. The police take him away and leave him in front of Mrs. Lindley's home.

34. Edward returns immediately to Alexandra's home and locks himself with her in her room.

35. Monday, October 28, Mr. L. calls the police, in charge of minors. They arrest Edward and keep him until Tuesday morning in a cell at Carl-Vogt. After this experience, he swears that he will not be taken again.

36. On November 4, Edward goes back to Alexandra's. Mr. L. takes out a penal complaint against Edward for breaking and entering.

37. Judge J-L.R., who is in charge of instructing the complaint brought by Mr. L., pronounces a warrant for the arrest of young Edward who is placed in preventive detention during almost a week at the Clairière, taking into consideration the high risk of subsequent offense and the L.'s statement that Alexandra should leave Switzerland soon.

38. In an interval, Mr. and Mrs. L. separate and Mrs. L. has a new apartment where her children live. The mother of Alexandra allows Edward to live at her apartment. Mrs. Lindley agrees on condition that Edward promises to go to the Fontanelle for an assessment on Tuesday, November 19.

39. On Tuesday, November 19, in the morning Edward disappears and a notification of disappearance is made immediately.

40. From November 19 to 27, Edward calls his mother twice to tell her that he is in good health, and that he is staying "with a friend in Lausanne".

41. On November 28 at 1 :30 the customs office of the Bourget airport call Mrs. Lindley to tell her that Edward has just arrived in a private plane coming from Morocco. He is with Mrs. L. and Alexandra. The French authorities are asking to know if this minor is travelling with his parents' permission. Mrs. Lindley explains that he is currently being sought by the police, but the customs' officers let him go.

42. Edward calls his mother several times from Mrs. L's apartment in Paris, thus giving her the telephone number.

43. On December 2, Mrs. C.Q. of the Youth Protection Services calls Mr. S. to inform him that the Fontanelle is ready to see Edward on Tuesday, December 3, at 18:00. Mr. S. calls Edward and explains the situation. On the morning of December 3, the police call Mrs. L. who puts Edward in the first train for Geneva.

Entry in my diary dated December 9, 2002:

Talked to Chantal this morning. She said to me that when I say I want Edward "se calmer et se poser" that it sounds like a projection.

This is it – 8 days to go and he will fly off. He may have his wings clipped by the educational measures and the guardianship, but he is off and I watch him go.

What sadness – it is not the way I would like it to be. I don't feel sure that he has the right baggage. What guilt for not having found out earlier – for having organized a better learning environment.

What relief – I've had enough of the lack of respect. It would or will be nice not to have to worry about the daily grind of life with Edward.

C.Q. says he will meet his destiny no matter what. Richard said he is here to learn social skills and it is not my task to teach it. Jean-Luc says it hurts him to see me in this difficult place where there is no answer.

Say goodbye to your illusion! My son is nearly 18 and he is off.

Legal brief to the guardianship court from our lawyer, Alex R., dated December 9, 2002, stamped as having been received by the guardianship court on December 9, 2002, translated from French:

Subject: The minor, Edward, born December 17 1984

Request for guardianship with provisional urgent measures

E-mail from Mrs. C.Q. to Jean-Luc, dated December 11, 2002, translated from French:

I found myself alone at the meeting at the Foyer Pont. Edward passed by my office at 12:15. He said he was ready to spend a couple of days at the Pont, but the place was already taken. The waiting list is more than gigantic. To be brief, the ultimate chance is tomorrow at the Foyer Breuleux. But it will be the same, if he does not turn up for the meeting, the place will be given to someone else within the hour. Be in touch soon.

E-mail from Jean-Luc to C.Q., with copy to me, dated December 11, 2002, translated from French :

Subject : Edward

Just in case you were wondering, it seems he is back at the L.'s :-)))

Entry in my diary dated December 15, 2002:

Tears – there is nothing to look forward to.

Edward has gone off since Friday to find his fortune, full of recriminations against me. I wrote a story this weekend about a mother who let go. We haven't booked to go away. We have had digestive problems. We went to the chalet. I come back and find it so oppressive. There is nothing to look forward to. Is that really so? I want to look forward to Edward's success.

The story

There was once upon a time a mother. Her son was born in the winter time, in the year when it was so cold that the people could ski in the town. He was like a ray of sunshine, a golden boy with a halo of blond hair around his round face. His blue eyes looked inquiringly at his mother and she loved him.

As the years passed, the mother realized her son was different from other boys. He had great temper tantrums and took risks that other boys didn't take. He could be charming and mischievous. He didn't do well at school, he didn't fit in with the others, and she loved him.

And when the time came for him to become a man, nature did not do its job. The boy stayed a boy, now a tall, angular boy, who took different, more dangerous risks. And she knew he was different.

He did what he wanted to do which was not what other boys do. He no longer went to school. He told stories of how he had suffered, how unhappy he was, and how he couldn't do what was expected of him.

And she, his mother, tried so hard to find a place for him to be, a person to teach him what he needed to learn, a doctor to push nature along, a therapist to

listen to his woes. And she hoped that, in spite of his difference, he would grow up and find his place in life.

But time went by and her son did as little as possible. He spent his time idly in childish occupations with rich, vain playmates. He indulged himself with money taken from the purses of friends and his family. And his mother's heart ached. And soon it came to be that he reached the age of maturity and he could do what he wanted to do. What he wanted to do doesn't pay for food and shelter, but he had to learn for himself. And so on the day of his maturity, he left his mother's house. And her heart ached knowing that her son was different, that her love could not turn him into a man, but she hoped and prayed that he would find the strength inside himself to find his place in life.

Letter to the guardianship court from Alec R., our lawyer, dated December 17, 2002, and stamped as having been received by the guardianship court on the same date, translated from French:

I intervene in my role as legal counselor to Mrs. Katherine Lindley, mother of young Edward.

Because I cannot get in touch with you by telephone, I am writing to you to ask you about the situation concerning our request made on December 9.

Young Edward celebrates his 18th birthday today and is therefore of age and thereby the sole master of his life.

As we have already shown in our brief, Edward is not able to manage his own affairs in reality, and to take decisions concerning his future. Considering his serious problems, Mrs. Katherine Lindley has decided to take necessary steps to have her son integrate an establishment in Valais. However, knowing that her son is now of age, Mrs. Lindley is aware that her son can decide by himself to leave the establishment and put himself and others at risk.

The above-mentioned motives bring my client to request the guardianship court to take provisional and urgent measures to assist and protect Edward during the procedure. My client is extremely worried that her son may have uncontrolled behaviours and attitudes again, and that he is unfortunately incapable of evaluating the consequences thereof, compared to other young people of his age.

In view of this, I would appreciate if you inform me of your decision to proceed concerning our request and especially your conclusions about the provisional measures.

Entry in my diary dated December 24, 2002:

Edward came by at 12:00. I told him we would prepare his bag with clean clothes. He asked me why I was crying. I said I'm not a happy person. I told him I'd put his Xmas present money on his bank account. He left and called me to say that he couldn't get his money out. I told him it wasn't my problem. I packed his bag and put it outside the front door. He came back and rang the doorbell around 17:00. He had 2 CDs, one for me and one for Jean-Luc. He left. I cried and cried and cried. He went to stay at John's.

2003, the year Edward tried to end his life

Entry in my personal diary dated January 6, 2003:

My analysis session with Evy: the dream shows that I am no longer trying to be someone I'm not. I'm learning to be myself. I nourish myself. I do what I want.

Copy of the official warrant for arrest established by the police dated January 9, 2003, in French:

Edward is wanted for breaking and entry.

Entry in my personal diary dated January 20, 2003:

My analysis session with Evy: this dream reflects my anxiety for Edward. My father is the father figure. John is just not there.

Letter to Dr. P.-C., Service Médico-Pédagogique, Geneva, dated January 21, 2003, translated from French:

We have been trying to contact each other since the month of December without much success. Therefore I am sending you this request by letter.

Edward has started his psychotherapy sessions with Berthe since the month of October 2002, and he wishes to continue on a weekly basis. [Berthe] told me that the treatment has to be approved by you for it to be paid by the disability insurance. Could you please do a new prescription? Our respective telephone numbers are the following:

Entry in my personal diary dated February 2, 2003:

Edward has not been seen since Monday, after he returned my car and key that he stole on Monday.

Dreams – feelings of anxiety. I wish I knew that he was all right. I hope he is all right. It feels like I have to cut him out – or he does things that are unacceptable, like stealing my car. We have to take distance, but will that really

help him? Does he have what it takes to become autonomous without putting himself at risk? Did I teach him that much? It's so tiring to be anxious. How long do I have to be anxious, to prove that I am a good mother?

Sunday evening:

Edward called to say that he was going to commit suicide. First he talked to Bea, and then to me, and then to Jean-Luc. I told him to go to the psychiatric ward.

Entry in my personal diary dated February 3, 2003:

I saw Evy. I wrote to the judge, copy Alec and C.Q.

Letter to the judge T.L., copy Alec R. and C.Q. dated February 3, translated from French:

I tried to call you this morning. The telephonist told me that she had 12 telephone lines to manage, that she could not put my call through to you or your clerk, and that she did not have time to listen "to my life story".

I am writing directly to you, with a copy to my lawyer, Alec R., because my son's situation has become too difficult for me and his sister, Beatrix.

On January 26 at 4:00 a.m., my son woke me up to tell me that he had nowhere to sleep because his girlfriend, Alex, could no longer put him up as she normally does because her mother was back in Geneva. Her mother took out charges for breaking and entering on January 9th, and he spent a night in prison. On January 27 in the afternoon, Edward stole the key of my car and then my car. He returned the car, damaged, on January 28. I asked my lawyer, Alec R. to press charges against him. Since then, until yesterday evening, I heard nothing from him.

Yesterday evening, Sunday, February 2, at 22:00, my son called his sister to tell me to call him back on his mobile phone because he was going to commit suicide. I called him immediately and he told me he had nowhere to sleep, that he had no more money and that he was at the end (of his strength). I told him that I couldn't open my door to him because he put us at risk, and I told him to go to the psychiatric ward or the police.

His psychotherapist, Berthe, told me that she has not seen Edward for his weekly sessions for the last two weeks. She told me that she finds that he is a very precarious situation and his physical health is at risk. He has not followed up on the steps that were recommended to him by Mrs. C.Q. of the SPJ in December, to go to the Employment Office and the General Hospice (social assistance). He has been to see Dr. J.C.C. for the medical report, established with information from Dr. H., psychiatrist, of the Service Médico-Pédagogique, for the medical examination at the Military recruitment service on January 27. According to this medical report, as explained to me by Dr. J.C.C. Edward is inapt to do his military service for psychiatric reasons.

I request that you undertake measures to put my son, Edward, in an adapted structure. My request for him to put under guardianship was made in the beginning of December. I cannot ensure the supervision of my son. He is left to his own devices since December 22. He has clearly shown that he is inapt to take care of himself for psychiatric reasons. He needs to be in a supervised environment, even if it has to be imposed upon him.

I am also requesting that the Youth Protection Services put in place protective measures for his sister, Beatrix. Beatrix suffers enormously from the situation, to the point where she is repeatedly ill.

I do not wish to be hospitalised in the psychiatric ward again, as I was obliged to be in May 2002. I wish to live normally with my daughter. Is it too much to ask?

Entry in my personal diary dated February 4, 2003:

Edward came by in the evening. I told him he was not coming in anymore.

E-mail from Jean-Luc to Alec, our lawyer, on February 6, 2003, about the below letter to the judge, translated from French:

I am not in the greatest shape, but what I want to say is, it is not that I don't give a damn and that the court can decide what it wants, but

- *It is perhaps not a good idea for me to be his guardian right now because he may be under the impression that he can manipulate me more easily than an external person*
- *I am not closing the door. I remain willingly here to help him and support him as soon as the disciplinary problems have been resolved.*

Letter from our lawyer to the judge T.L. dated February 6, 2003, translated from French:

You know that I am the legal counsellor to Mrs. Katherine Lindley in the above-mentioned procedure. Mrs. Lindley has asked me to tell you of the recent, serious events which have led her and Jean-Luc S. to close the door of their home to young Edward.

Edward does not want a guardianship measure to be installed, although it was the case when we addressed the request to you. Mrs. Lindley considers, however, that the request she addressed to you on December 9, 2002, requesting the installation of guardianship and deprivation of freedom with the aim of assistance in favour of her son, remains totally pertinent.

Concerning the choice of guardian, the current situation leads us to think that Edward would no longer wish Jean-Luc to be his guardian, even though Jean-Luc continues to want to help him. Our client leaves it to the court to decide with the precision that Jean-Luc remains at disposal if his designation would be agreed to by Edward.

Entry in my personal diary dated 21.02.2003:

Barbados

Letter from my mother dated February 24, 2003:

First thank you and Jean-Luc for the lovely meal on Friday night – and also for the days in the chalet. We called Eddie and he joined us at Pizza Hut for supper. He was very sweet and I think quite pleased to join us, if a bit hesitant at first. I hope we did an OK thing. We didn't let him in the flat. I implied you were back Saturday.

Letter from Edward dated February 24, 2003, translated from French:

Dear Mummy,

How are you? I hope you had a good holiday with Jean-Luc. I didn't quite understand what your mother told me about where you had gone to, but ok. On my side, things are going gently forward. I succeeded in getting back my job at the pharmacy. I pushed my luck with the boss, and it was done. Oh yes and before I forget, I was reconciled with Mrs. L. and she is letting me sleep at her place. The L. family has left for Mauritius for a week and a half, and Mrs. L.

left the keys of their apartment. It is really nice of her. I think a lot of you nowadays, and I wanted to excuse myself for having taken the car and scratching it. I would like to gain your confidence.

If you would like to write to me, that would be good, but not at the address here. Send me a message and I will come and pick it up.

PS I send you big kisses. I hope the cats are well. I love you and send you big kisses.

Entry in my personal diary dated March 2, 2003:

Yesterday Jean-Luc started hassling about the project... I got defensive. The analysis of my dreams show that I'm ignored and yet in real life I am standing up for myself and my views. But because it is not typical for me to stand up and defend myself, I am uncomfortable. There is an imbalance.

Letter from Alec R., our lawyer, to Mr. Y.B., Edward's lawyer, dated March 11, 2003: translated from French:

You know that I have been requested to defend the interests of Katherine Lindley, mother of Edward.

My client informs me that you called Mr. S. to inform him that the young Edward "made a serious fault" against Mrs. L. and that he is in possession of an arm.

Considering the gravity of the reported facts, it seems most important that you inform the judge T.L. so that he can take the appropriate measures – that he informs the police that Edward is in possession of an air pistol – to ensure that further damage can be avoided.

Letter from Alec R., our lawyer, to Judge T.L., guardianship court, dated March 13, 2003, translated from French:

It has been reported to my client, Mrs. Katherine Lindley, that her son, Edward, "made a serious fault" against Mrs. L., the mother of his girlfriend, Alexandra, and that he is in possession of an arm.

Considering the gravity of the reported facts, it seems most important to inform you so that you can take the appropriate measures, to inform the police that he has an air pistol, so that we can avoid further damage.

My client is extremely worried that her son has uncontrolled actions and attitudes again, and that he is not able to measure the consequences of his acts, compared to other young people of his age.

I would be grateful to you if you could follow up on the request for provisional emergency measures, which was addressed to you on December 9, 2003.

Entry in my personal diary dated March 14, 2003:

Edward is in the psychiatric hospital, Belle Idée, since Thursday evening. He was stopped from jumping off a roof.

Letter from Alec R., my lawyer, to Judge T.L., guardianship court, dated March 14, 2003, translated from French :

This letter is an addition to the letter addressed to you yesterday.

A serious event took place yesterday afternoon. Young Edward tried to end his life. Edward was taken to the psychiatric emergency ward by the police and is now at the Clinic Belle-Idée. These happenings show, as if there was a need, that the aggressive and suicidal behaviour of Edward not only threatens his own security, but that of others. It is now obvious that Edward requires regular and strict supervision, and that his placement in an institution is evident and urgent. Mrs. Lindley, therefore, requests, yet again, that you order the immediate internment of Edward in an appropriate establishment and a medical examination.

Letter from Judge T.L. to the direction of the Clinic Belle-Idée, with copies to Alec R., and Y.B., Edward's lawyer, dated March 18, 2003, translated from French:

We inform you that we have been requested to proceed with the deprivation of freedom with the aim of assistance, and denial of freedom, concerning Edward. We have been informed that the subject was recently hospitalised in your establishment.

We therefore request that you address a medical report certifying whether the subject fulfils the requirements of installing a placement under guardianship (art. a CCS), which are the following:

Guardianship

Article 369 al. 1 CCS "Will be assigned to a guardian, an adult who, for reasons of mental illness or weakness of spirit, is incapable of managing his own affairs, who cannot be without medical assistance or permanent help, or who threatens the security of others."

Article 370 CCS: "Will be assigned to a guardian, an adult who by his prodigality, his drunkenness, his lack of civility or his bad management, exposes

himself or his family, to fall into financial need, who cannot be without medical assistant or permanent help, or who threatens the security of others.”

Article 397 a CCS: “An adult or deprived person may be placed or retained in an appropriate establishment if, because of mental illness, weakness of spirit, alcoholism, drug addiction, or a grievous state of disrepair, the necessary personal assistance cannot be given to him in another form.

We also request that the medical report should state whether Edward has sufficient discernment to be heard correctly by the court concerning the installation of guardianship measures.

Letter from Alec R., our lawyer, dated March 19, 2003, translated from French: *Please find attached the letter from the guardianship court addressed to us on March 18, 2003. As you can see, the judge T.L. has requested a medical report on Edward’s health from the Clinic Belle-Idée.*

You will also find attached a copy of Dr. J.C.C.’s letter to the guardianship court, dated March 7, in which he states that he has not been relieved on his confidentiality, and that he cannot establish a medical report.

Letter from the administration of Geneva University Hospital to Judge T.L., guardianship court, dated March 26, 2003, of which a copy was sent to Alec R. on April 2, who sent me a copy of April 7, 2003, translated from French: *Your letter dated March 18, 2003, addressed to the direction of the Clinic Belle-Idée, concerning Edward, has been transferred to Dr. A.M., first head of clinic at the unit where the patient is currently hospitalised. Dr. A.M. will respond to your request as soon as possible.*

Document from the Police, Department of Justice, Police and Security, State of Geneva, dated March 23, 2003, translated from French:

Declaration

I, the undersigned, Edward, (personal details),

Take note that I am being heard as the defendant, presumed guilty of breaking into, and being arrested on the roof of the university today. I have been given knowledge, by the reading of a document, of my rights according to the article 107a of the penal code.

“About 15 days ago, I told the police that I wanted to commit suicide by jumping from the roof of the university. The police arrived on the scene and managed to control me. Taken to the cantonal hospital, I was consulted by

doctors and interned in the psychiatric clinic, Belle-Idée. I wasn't very well.

Since then, I have been under treatment. My doctor is Dr. D.

Yesterday afternoon, I ran away from the establishment for four hours before returning. Today my doctor allowed me to go out from 2 to 6 p.m. These days I don't get along very well with my girlfriend, I don't know where I am at, and I want to commit suicide. Leaving the clinic, I came down into town with my roller skates. My intention was to go up to the roof of the university to try to commit suicide again. When I arrived at the doors of the university, I damaged a sliding, glass door with my roller skates. Then I climbed up on to the roof. It is there that you found me.

I am aware of the damage that I did to the entrance door of the university, and I commit to paying the repairs.

Personal situation:

I am the eldest child of the family. I was born in the Clinic Grangettes. I have a little sister called Beatrix. My mother is a trainer and my father is a director of an international school. They got divorced in 1992. Following the divorce, I lived with my mother until I was 18. When I reached civil adulthood, she threw me out of the house because I was doing only stupid things. Currently, I have no fixed domicile. I was living with my girlfriend for three months. My mail is still addressed to my mother's domicile. I am still registered at her domicile with the Inhabitant Control Office. I still keep contact with my parents. I followed first and second grade in Satigny, then the third grade in Meyrin. After that I went to the international school in Versoix, then three years at the Farny School, and then one year at the Passerelle in Vesenaz. My parents then put me in boarding school in La Foully. To finish, my mother placed me for one year at the SGIPA, a pre-apprenticeship school.

I confirm that I have knowledge of my rights according to the article 107a of the penal code, of which I received a copy."

The above report was attached to a police report, dated May 14, 2003, in which Edward's doctor, Dr. C.D. at the Clinic Belle-Idée was quoted as follows, translated from French:

"I am the doctor supervising young Edward. He was hospitalised in our establishment following a suicide attempt about ten days ago. Today, he was given a small permission to go out for four hours and was supposed to return at 18:00. Edward is totally responsible for his actions. I am surprised to learn that he tried to commit suicide again."

Entry in my personal diary dated March 30, 2003:

Edward has been in Belle Idée for 2 and a half weeks. He tried to kill himself again. He has run away. He has been admitted on a non-voluntary basis. On Friday, the 28th, he was so sad, so depressed. When I left, I cried too. I saw him yesterday afternoon. Then he ran away again yesterday evening, and came home to us. We called the hospital. The security guard and police came to get him.

I wonder whether his sadness and depression are part of the acceptance process in Kubler-Ross's 'stages of dying'. 1. Denial, 2. Rage and anger, 3. Bargaining, 4. Depression, 5. Acceptance. If it were so, then he would be close to acceptance. I want to hope. I want to hope that he will accept to go into a structured environment that will help him.

Meeting with the doctors last Tuesday at Belle Idée. They are doing the medical examinations and they are in favour of 'deprivation of freedom in order to assist'. Edward showed us the range of his behaviors:

- *Seduction and arrogant charm*
- *Anger and emotional blackmail*
- *Victim and tears and more emotional blackmail*
- *Bargaining.*

Entry in my personal diary on April 3, 2003:

I am traumatized by Edward's escape on Sunday, and that he turned up on our doorstep.

Entry in my personal diary on Saturday, April 5, 2003:

Edward has permission to go out today from 2 to 6 pm and I'm worried about him. I've told him I'm around. I'm scared that he will try to see Alex and have an argument and try to kill himself again. I guess it's a test for him. I've told him I'll be at home and that if he needs money he should come by and get it.

Entry in my personal diary on April 12, 2003:

Loads and loads of pain and tears for Edward.

E-mail from my father on April 12, 2003:

We talked to Edward yesterday afternoon. He was just getting on a bus, I think. He said that he would enjoy us sending him something to read so we need an

address please. Glad to hear that you are having an Easter break in Barbados (?) – am sure you need it. You are very much in our thoughts and prayers.

E-mail to my family members on April 13, 2003:

Edward came out yesterday for the afternoon and we spent some time together and then he spent some time with his Dad. He is really calming down and taking it easy. He has more lucid moments and less paranoid moments. I don't know if it is the drugs or if being in the structured environment he can unwind. In any case the girlfriend has stopped pestering him, he is just having to cope with the break-up. His postal address is: HUG Belle-Idée, Unité Sillons 2, Chemin du Petit-Bel-Air, 2, 1225 Chêne-Bourg.

I don't know when the doctor will have finished his medical examinations and report to the judge. I do know that the wonderful social assistant who looked after Edward in November has been to see the social assistant at the hospital to discuss what opportunities or possibilities are available. I think this is absolutely great news because finally the two organisations are actually talking together! The social assistant of the hospital said that Edward would not be released from the hospital until he can move into another place. I have also started the paperwork for his invalidity pension. (Why do I have to do it? Cause no-one else can do it and I am his mother).

I had a really rotten day yesterday, loads of tears and anger about him being locked-up and feeling very helpless. It sort of hit me in the face. Jean-Luc managed to keep close until it was over which was very brave of him. Am sort of looking forward to going away on Thursday – yes we are going back to Barbados with Beatrix. She and I are travelling economy class. We get back on the 26th - Jean-Luc's 40th birthday! I will spend most of my vacation revising for my OU exam which is on the 29th. Yes I am working today cause I have a trainers guide to write for Wednesday. Stops me thinking.

Entry in my personal diary on April 14th, 2003 :

Major argument with Beatrix yesterday about the weekend, her father, her behaviour, Edward.

Letter from Mr. Y.B., lawyer designated to defend Edward's interest in the procedure, to Judge T.L., at the guardianship court of Geneva, dated April 16,

2003, translated from French. The judge sent a copy to Alec R. on April 16, who sent a copy to me, dated April 22.

Subject: Edward

In regards to the procedure, I would like to inform you that Edward has accepted the measure of guardianship requested by Mrs. Katherine Lindley for him. He has no objection that Mr. Jean-Luc S. be designated guardian.

Medical report from the Department of Psychiatry, Clinic of adult psychiatry, Hospital Unit Sillons-2, signed by the doctors Dr. A.M. and Dr. D. N., addressed to Judge T.L. at the guardianship court of Geneva, dated April 17, 2003, translated from French:

You were recently requested to place Edward under guardianship and deprive of freedom with the aim of assistance by his parents, and you asked us to establish a medical report.

In spite of his young age, Edward has already a heavy psychiatric past. Already in his childhood, he showed serious behavioural disorders, hyperactivity and attention disorder. For these reasons, he was not able to finish his obligatory schooling, and a recent neuro-psychological assessment showed he has reduced intellectual capacities.

At the age of 13, the patient attended a specialised boarding school, until he was 15. His attendance came to an end because of serious behavioural problems. Two years ago, he was diagnosed with Klinefelter syndrome. This is a chromosomal aberration which results in a lack of masculine sexual hormones. This discovery was extremely badly experienced by the adolescent patient at that point in time. His behavioural problems become increasingly aggravated. Edward presents both conduct disorders (risky behaviour and reduced delinquency) and self and other oriented aggressive acts. In situations of acute stress, he does not have the capacity to manage them rationally. He presents an extremely low tolerance for frustration. He has shown very violent behaviour against others, as well as himself.

On March 13, 2003, the patient was hospitalised, on a non-voluntary basis due to the emergency, after been saved by firemen on the roof of the university from which he wanted to throw himself.

The family is overtaken by their son's problems, and cannot have him live with them anymore. Various placement trials have rapidly failed.

The patient is hospitalised since one month in the Clinic Belle-Idée. We have managed to create a good relationship with Edward who is currently cooperative. He does not have a place to live, and we are looking for an

appropriate structure to welcome him. He needs a very structured and protective place to live long-term. Because of the lack of an appropriate structure, we do not yet have a concrete project to propose.

Concerning the request to place Edward under guardianship, it seems precisely adequate and necessary. The conditions of the article 369 al. 1 CCS are reached. The patient is incapable of managing his own affairs because of mental illness.

Concerning the request to deprive him of freedom with the aim of assistance, article 397a, the situation seems to us to be more complex. For the moment, Edward remains hospitalised, on a non-voluntary basis at the Clinic Belle-Idée. He is currently cooperating with the medical assistance and with the search for an appropriate place to live. Without having found an appropriate structure which will agree to take the patient in, it does seem useful to us to pronounce in favour of the art. 397. However if a place to live is found and the patient opposes it, then the prescription of the article 397 would be rapidly necessary.

Entry in my personal diary on April 28th, 2003:

Back from vacation. More or less ready for my exam tomorrow: my first step towards my Masters. Jean-Luc survived his 40th birthday. I'm being coached. What do I want to be now that I'm grown up. I want to break the ropes of obligation, work ethic, pious hard-working, no-fun life. I want to be adventurous and go-ahead.

E-mail to my family members on May 5, 2003 :

Subject: Edward update – some good news

Just wanted you to know that he is making progress.

He has read a book from cover to cover for the first time in his life - Harry Potter in French.

He has read more than 30 pages in English of one of the books that Gran and Granddad sent him, on Chris jr's recommendation. He has started classes with his old teacher, Mrs. Iovino, twice a week and has done his homework.

Jean-Luc and I went to the 'family meeting' today and got some things moving for him. There were two doctors, two nurses and the social assistant there.

The doctors report to the judge states that Edward is in need of a 'tutor', but should not be deprived of his freedom as he is collaborative.

Edward is set to start his psychotherapy again. He has been really sad lately which the doctors see as a 'healthy sign'. Seeing that the above two indicate that he is doing ok, 'we' will not wait for the judge to place him, but will start

investigating the options for him. I have to be careful here because I must not do too much.

Edward and I are going to see an institution in Lausanne next week, a place that is highly recommended, where he can do a number of activities - and go to school. This place is considered "la crème de la crème", but Edward does not really want to be in Lausanne.

Jean-Luc also said that since Edward would prefer to stay in Geneva, the social assistant should make sure he gets to visit the places where he could go to in Geneva. In fact, Jean-Luc got a little stroppy with the gang - and was rewarded with an enormous bear hug from Edward afterwards. (He was also screened by the inmates, a rather harrowing experience. It was when he got to the door and found it locked that he had a moment of panic, but again like last time, they let him out.) The social assistant was so 'nice' to Jean-Luc, "such a wonderful man". I'm just the mother.

John is out of the loop at Edward's request. I find it rather a relief because I do not like it when I hear John talking about his son and saying, "the fucking little bastard". I have had enough grief from that asshole. But I am not telling you all anything new, right?

E-mail from my father on May 6, 2003:

Wonderful to know that Edward is making progress and we pray it will continue. There are bound to be hiccups but I hope there is enough wisdom in his carers to overcome them. Jean-Luc is a brick. So sad that Edward's father has so little understanding, love and compassion. Thank God his mother has all three in abundance.

E-mail from my brother, Matthew, on May 6, 2003:

Good to hear your positive news. I'm still surprised by John's attitude towards Edward (after all this time) and yet it is also sad that John cannot see what he has done and continues to be so negative. Next time he is abusive about Edward, remind him of English saying "Takes one to know one"!

E-mail to my family members on May 11, 2003 :

Subject: Getting Edward out of hospital

I took Edward to see this institution on Friday afternoon. It is in Lausanne, in the middle of the town, in one of the little paved St.s. The place is called the Institut Maieutique (which comes from Greek for Scholars, to your dictionaries! I think development). It is run by a very cool guy, who wears black

and has longish hair, and I am not sure if he is a doctor, but the place has been going for 50 years.

Mr. Serero saw us for about 30 minutes and asked Edward loads of psy-questions like, "Do you think your parents should worry about you? What worries do you have about yourself?" and then did a brief explanation about the place in regard to Edward, such as "You will never find a place where you like everyone. You will have to make some concessions. Here the people are young adults, but not everyone has the same difficulty.

There has to be a project (this is a FAVORITE word amongst social assistants and educational psychologists, Jungians do not talk about projects) and there is a program to help achieve the project. No hanging about, young man, you will have to do school work, sports, and cultural activities. (This sounds great. I would like to go myself.) It is a hospital. The care is provided by specialists (who know better than anyone else) and it is paid for by the insurances. Some patients just come in each day; others stay in 'protected apartments'. In fact, the apartments are progressively more unprotected / open so as the patients become more responsible, they move towards a 'free-er' environment. There are rules and regulations to be respected. Admission is on a voluntary basis. Edward can call when he is ready to spend a day in the place to see what it is like. If he does not accept to go to this place, he will spend his life in worse places doing 'institutional tourism'.

Edward did not ask any questions, he became increasingly mesmerised by the guy's charm and was charming in return. He thought it was pretty cool and when we came out, he found a piercing shop in the St. and went and bought a new blue and white stud for his pierced tongue. No, I didn't accompany him. Yuck.

I found out yesterday that the money he had on him came from his sister's purse (he popped in on Friday afternoon before we went) and not like he told me from the pocket money fund at the hospital. So I didn't make him the chocolate banana cake I had promised him, and I didn't go to visit yesterday – and I paid Bea 45 francs back. Some things don't change.

And to please myself I went (on my own) to see Saltimbanco, the Cirque du Soleil, yesterday afternoon. If you have the opportunity to go see it, do. It is

wonderful and breath-taking at moments. But, like all circuses, the clown is either funny or not – and in this case, I didn't find him funny.

Entry in personal diary dated June 11, 2003:

I went to see a homeopathic and medical doctor yesterday, Dr. C., who told me to do two things. The first is to take Sepia on prescription, the second is to tell myself many times a day that I'm "divine, genial and wonderful", to start loving myself.

Tapping EFT (Emotional Freedom Techniques)

Fax to Edward's lawyer, Yves B., dated June 17, 2003:

My son, Edward, did not receive convocation to the hearing due to take place this morning at 9:50 a.m. at the guardianship court. As he has elected his domicile with you, I suppose that you must have received the convocation and informed him.

Dr. A. M. has organised Edward's transportation to the hearing, and has asked me to enquire about your presence. I leave it to you to contact Dr. A. M. at the hospital. You may contact me on my mobile phone.

Entry in personal diary dated June 18, 2003:

Yesterday I was the saddest I have ever been. We went to the guardianship court and Edward was put under guardianship, deprived of being totally responsible, and Jean-Luc was named guardian. I cried a lot.

Entry in my personal diary dated June 23, 2003:

The obstacles have increased. Jean-Luc's company is going bankrupt. René (our neighbour) is going bananas about the money Edward owes him. Stupid or mean?

Jean-Luc is on medication for depression.

The heat-wave is back.

I'm getting uptight.

Letter from the office of Alec R., our lawyer, dated June 23, 2003:

Mr. Alec R. presents his compliments and asks you to find attached, for your information, a copy of the minutes of the hearing that took place on June 17, 2003.

Attachment : Letter from the guardianship court, Ministry of Justice, Geneva dated June 19, 2003, addressed to Alec R., dated June 19, 2003:

Subject: Edward

The judge, T.L., presents his compliments and sends you, attached, a copy of the minutes of June 17, 2003.

Minutes of the personal presentation and inquiry

In the year 2003, Tuesday, 17 June,

Before T.L., judge, presiding magistrate,

And M-F.B, court clerk,

In the case of Edward

The following proceedings took place in the interrogation of the parties:

The persons present:

Edward, assisted by Y.B, lawyer

Katherine Lindley, assisted by Alexandra L. replacing Alec R.

Jean-Luc S.

Mrs. Lindley:

I confirm my request for my son, Edward, to be placed under guardianship, and for Mr. S. to be nominated as his guardian.

Edward:

I confirm that I agree to be placed under guardianship and that Mr. S. be designated my guardian.

I am still at the Belle Idée clinic. I think I will leave this establishment in about a week and start living at the Foyer des Bains.

I have no employment nor any source of revenue at the moment.

Jean-Luc:

I agree to be designated guardian of Edward, under condition that the doctors think that it is a good idea!

Effectively, we have had some tensions before now.

I do not wish my designation to perturb Edward.

I am a computer scientist.

I have never been bankrupt.

I know the responsibilities of guardianship.

Edward:

I confirm that I agree for Jean-Luc to be designated.

You inform me that if this measure is not convenient, I will not be able to end it on my own accord, but I will have to apply a request to this court.

Has been heard as witness:

Dr. A.M., first head of clinic, Clinic for adult psychiatry HUG, neither parent, nor friend, under oath:

I confirm the contents of the report I addressed to you on April 17, 2003.

I confirm that Edward, apart from Klinefelter's syndrome, suffers from a personality disorder and slight mental retardation, disorders that can be assimilated to a mental illness. I confirm that due to these disorders, Edward is not capable of managing his own affairs.

I confirm, also, that in acutely stress situations, Edward can threaten the security of others.

I confirm that it is foreseen for Edward to integrate the Foyer des Bains when he leaves the Clinic Belle-Idée. We have still not received a formal agreement from the Foyer, at this point in time.

Edward requires supervision currently. If Edward continues to cooperate, as he has done so in the recent past, the supervision provided by the Foyer will be sufficient. In my view, it should be a placement for at least one or two years.

I do not think that the nomination of Jean-Luc as his guardian will prejudice Edward's health. However, I ask myself if it would not be preferable to designate a totally neutral person, considering the conflicts that could arise between the guardian/step-father and the pupil. In the current situation, I do not see a formal contradiction in designating Jean-Luc as his guardian.

In the current situation, and seeing Edward's cooperation, I do not think that a measure of deprivation of liberty in the aim of assistance is necessary, as long as he agrees voluntarily to his placement.

To reply to Ms. Alexandra L., in the case that Edward would not cooperate with the Foyer des Bains, there is obviously a risk that he will be hospitalised again,

and that a search for another place to live, perhaps in a more appropriate establishment, would be undertaken.

To reply to Mr. Y.B., Edward was, at moments, aggressive and violent at the beginning of his hospitalisation. He ran away. However his behaviour has improved and thanks to his cooperation, it has been possible to find him another place to live besides the Clinic Belle-Idée.

To reply to Ms. Alexandra L., I confirm that it would be indeed an advantage for Edward to catch up on his school deficits and to acquire a professional qualification. This project could be developed at the Foyer des Bains. However, there are steps that should not be ignored, and he will first have to integrate the Foyer. I confirm that Edward wants to stay in Geneva.
End of the hearing of Dr. A.M.

Jean-Luc:

After hearing Dr. A.M., I confirm my agreement to be designated guardian of Edward.

Edward:

I confirm that I wish Jean-Luc to be designated guardian.

The next step in the procedure:

The procedure to deprive freedom with the aim to provide assistance is closed, under reserve of new facts.

E-mail from my friend, Gerry, on June 22, 2003:

Re: News about my son

I really feel for you, and I am sorry that I had not seen your e-mail before, so I could not even talk to you about it when we met at Ioana's party. I do admire you for all your courage and all the wonderful things you have done and are doing for Edward as much as you can. I hope that the crying has helped and that you are coping as well as you can with the situation. It is great that Jean-Luc is so supportive and loving – you do deserve all the love and the support, not only from him but from all your friends, among whom I am proud to consider myself, who love you very much.

E-mail from my friend, Chantal, on June 22, 2003, translated from French:

Just to tell you that I understand your need to stay with yourself during this terribly hard time. Let the weight of all these words that have hurt you, wounded you, caused all this suffering, be released by your tears. Above let go of the judgment that our society gives because of the fear. Edward has all my affection, all my respect and all my best wishes. To you I give you all the years of friendship, the solidarity of women and mother and, above all, all my confidence in your strength of life. With all my heart with you, Chantal

E-mail to my friend and neighbour, Sylvie, dated June 23, translated from French:

I don't know how to write to you because I am still quite upset after what your husband, René, said to me last night, and I say to myself after all the shit that we have had recently (we have just come out of the guardianship court where my son was declared mentally ill) we are now going to lose a friend.

I don't know what was the agreement between René and Edward concerning the stolen money. I asked René last year if he was satisfied with the agreement that he had with Edward, and he answered that he was. It seemed to me that he had forgiven Edward and now he is at my door asking for the money. I don't know how much money we are talking about. He doesn't know if there was a complaint deposited with the police. I have the impression that we are going into a story where there is a lot of emotion and not many facts. I cannot face this story right now. I spent last night crying. Until this story is solved legally,, as we asked you to do last year, I cannot see you.

Edward has legal assistance from the lawyer, Y.B. (contact details). He is currently at the Sillons Pavillon at the Clinique Belle-Idée, and his doctor is C. D. (telephone number). I think that René could talk to these two people to find out what legal and pedagogical approach could be used, and how he could be reimbursed by Edward.

E-mail from Sylvie on June 23, 2003, translated from French:

First of all I want to tell you that we, René and I, hesitated for a long time before talking to you about this, but seeing the time go by, we realized that you most probably thought that the problem was solved, each thinking that the other had given the money back (it concerns 200 pounds and 700 euros, a sum that Edward agreed to without a problem.)

I remind you that the first time it happened you gave me back the money that Edward had taken from Julie straight away and afterwards you asked me to talk to him which I did. You had the immediate reaction of a mother and friend, the same reaction I would have had if it had been my daughter, a reaction which puts things back in order and, as we are friends, to be able to talk to me openly without me being judgmental.

You talk of forgiveness. Both René and I have never held it against Edward. I think our behaviour has shown that. You know that I like him very much. He came to see us regularly to have dinner with us, watch the television, talk, ask for advice, play with Julie. René sincerely tried to help him and you. He talked with Edward for a long time trying to understand what motivated him to steal. I remind you that you asked him to do it, the goal being to put him in front of his responsibilities. So René told him off and got an agreement that he would pay back the money bit by bit according to his possibilities. René talked to him in this way to please you, he knew that Edward would never be able to pay it back. You say that you asked René if he was satisfied with the agreement. I remember that he said to me that he didn't understand really what you meant. He was worried about what Edward had told him about his life and his circle of acquaintances and he wanted to talk to you about that, without any success. So I talked to Jean-Luc about it.

Concerning the complaint that was never completed with the police, I want to remind you of the facts. You asked me to undertake this procedure because the "flavour-of-the-month" psychiatrist asked for it. You knew how much we were against it. I went to the police station, told my story, talked to your ex-husband and Jean-Luc. The police thought it would be useful to organise a hearing with him to put pressure on him and to scare him. But if I had really continued the procedure, he would have found himself in front of a judge. I think seeing what we now know that it would have had negative consequences. Anyway I did all that and finally I was told to cancel it all ... I can't remember why but probably because Edward was going to live with his father. I did all that, like René talked with Edward, not with the goal to get my money back, but in response to your request, to help you, to try to help Edward. Never we would have thought of taking a legal recourse against who? Edward whom I love with all my heart, against you my friends? Are you stupid, where are we, on what planet?

I sincerely don't think that we are against you. I believe that we have always been there for you when needed. I think on the contrary that we are with you!!! (this to try and make you smile). And I think that we are more than just neighbours, we are friends who have shared so many things, like champagne, good meals, worries, fears and all of that.

You cannot hide behind the legal recourse and say that you are not going to talk to me until it is solved. That is running away from reality. This is not about a stranger who has had something done against him, this is your friend from whom your son stole money. I repeat if it had been Julie you know very well that I would have paid you back immediately and I would have appreciated your listening and help.

You know very well that René and I will never call the lawyer nor the doctor. An action like that would be scandalous only done by cowards. I asked you if I could go and see him and you said it was too early. I wanted to see him, not ask for my money back. I don't give a damn about the money. I am lucky not to need it, I can continue to live normally, to go to restaurants, go on holiday, like you. My mind works differently from yours. You think of legal recourse, I think of human rapport.

I was sure that you and Jean-Luc thought that the story was solved by one of you straight away and that you never talked about it again between the two of you. It has been more than a year that René and I haven't dared to talk to you about it because with everything going on, money isn't important. When René finally talked about it, he expected a whole different reaction like, sorry I didn't know, I didn't think anymore about it, we will pay you back straight away, etc. etc. In short everything that I would do, because you know me if it happened to me I would be so embarrassed.

I don't know what kind of attitude to take. Neither René nor I want to make you cry. Contrary to what you say, it is about facts and not emotions.

All the courts, the psychiatrists, the doctors and the lawyers of the world will not change the fact that Edward is ill. You will only be able to help him when you accept this reality. If you want to delegate this role to institutes or courts you will only put him in more danger. I know that I am meddling in your business, but having seen you these past nine years gives me some prerogative.

You know how much I was reticent about the medicalization and this delegation to all these psychiatrists who would give each their own version. Today I have the impression that all these years and all these people have perverted your judgement, annihilated your judgement. All these good people have taken you away from the reality.

Please do not see us as the enemy. Try to put yourself in our place. What would you have done? What do you suggest that I do? I cannot believe that you are like this, nor Jean-Luc.

I stop here. I hope that I can send you this message this evening. I would like to talk to you alone or with Jean-Luc quietly without emotions that block everything, without judgement, talk freely as friends.

Reply to Sylvie on June 24, 2003, translated from French:

I asked for a respite, I receive a lesson on morality. You tell me stuff that you have been thinking for years, that you haven't told me, and yet you should have. I did not ask you to take me to court on motherhood. I totally agree that we are on different planets. I don't know if my planet is better than yours, it's different. We knew anyway, but we were friends – and for me to be a friend means to accept the way the other sees things. Don't you think that we have theories about your family the way you have theories about ours?

What I learned during the past five years of psychology studies is that there are multiple theories about human beings, that reality is nothing but a personal construction, sometimes cultural or social. There is not one theory that satisfies everyone, that everyone agrees to. It doesn't stop us from living together, or next to each other, without having to remind the other constantly of his weaknesses.

You have told me loads of things that I wish you hadn't told me in your letter because I won't forget that you said them. I could forgive you but I have an anger against you like I have an anger against the doctors and the services that say loads of similar things.

You have no idea what it is like to have a child with a cognitive retardation.
When you have accepted this, and you tell me, and you stop saying all the things that you say, perhaps we can pick up the discussion.

I will go through your e-mail to find the facts, to try to construct something. If I understood correctly you wanted to be reimbursed straight away. You did not say so. You didn't say that Edward took 200 pounds before he took 600 euros or 650 and now it is 700. I saw Edward yesterday and he told me that he agreed to reimburse 600 euros. You told Edward that he could ask you for money if he needed it. He told me that he took that as a permission to take money. Can you imagine me saying such a thing to your daughter, "if you need money, come and see me"?

You wanted it to be pedagogical for Edward. So I understood that you wanted to hold him responsible, not me. You had a discussion alone with Edward. Why didn't you ask me or Jean-Luc to be present? Because all these years you have been so pleased to listen to Edward confiding in you, and then boasting about it. Do I have the same behaviour with your daughter?

I didn't want to hear what Edward told you. How many times have we told you that Edward makes up stories? So, Sylvie, I am really angry. And I will go through your e-mail and I will ask the advice of my lawyer and the social assistant.

I asked for a respite, I got a slap in the face. When you needed support, we were there for you. We supported you; we didn't bring out theories about breast cancer to throw them in your face.

In a later mail I wrote:

You tell me to accept the reality but you don't allow me the time to grieve over my hopes for my son. You tell me I have delegated my role to the institutes and the courts, but who can take care of this so-called adult? Can you tell me who can do it, when my son refuses to cooperate with me? I believe this is your message, Sylvie, that I am to be blamed for giving birth to a child like Edward. Maybe because I even deserved it? Or maybe I made him ill? Obviously, compared to you, I am so far from being the perfect mother that you are. I hope our story comforts you in believing that.

An adult who has the mental age of a 13 year old, and who starts stealing, lying and who integrates that it is ok as long as you don't get caught. If it is about a reality that is not accepted, I think you are having a hard time accepting that the child you idealized has a mental retardation. René said to me the other

evening that having an IQ of 65 isn't important. Can you hear that? So tell me, Doctor of Psychiatry, what should I do?

Letter from Alec, our lawyer, dated June 27, 2003:

Subject: Your son, Edward

Please find attached the order given by the guardianship court on June 26, 2003.

Jean-Luc is, therefore, designated as Edward's guardian for an initial period of 2 years.

We will have an occasion to speak of this again.

Entry in my personal diary dated June 29, 2003 :

Jean-Luc has made four employees redundant, fired one apprentice. There remain three employees and three apprentices.

Sylvie (René's wife and neighbour) has bombarded me with shit via e-mail. Ben came from Marseille and we co-counseled. I was angry. I was also angry at her taking so much space and taking away my time for sadness.

Jean-Luc has been named guardian for two years. He will have to handle the finances.

We spent most of the day in bed. The heat-wave continues. I cried a lot in the morning. Found my sadness again. Good.

Edward came to supper.

E-mail to my father on July 1, 2003:

Say a prayer for Edward today. He will find out if he is accepted at the sheltered home where he wants to go. He has been spending quite a few days there doing different activities, he even slept over, and they seem to be happy with him, but there is a long list of people waiting to get into the place. It seems like he has got more fragile since being in hospital although it could be a good thing, like he is telling us what he has problems with. The doctor said at court that moving to the home was a big step and very stressful for him, and we need to go slowly. He and Jean-Luc seem to be happy about JL being appointed as his tutor (legal guardian). We have had the judge's decision. JL is appointed for two years, and then Edward will be reassessed to see if he still needs a tutor. Sigh of relief! The system is flexible! Actually I guess it is more like a 'power of attorney'. We went to see Edward together on Sunday and we sat on the grass and talked about it. JL is a little worried that Edward has chosen him as his new father. He told me afterwards how much he was too scared to have his own

children for fear that they would not be normal, and he ends up with me and Edward, and he just takes it on. We are still sad and grieving about it all. JL has had to make the decision to close down his company as it is not making any money anymore.... We signed the papers for our new company yesterday.... My part is The Training Spirit. I am almost ready to run with the new company entirely seeing I've got the logo and the website. Just need the new address for the business cards. We have looked at premises right near us downtown. We will start making the physical move in September. It should not have come as a surprise but it did. It seems like I have been here before (with Digital) and although I don't want to have to move (I am rather like a cat) I know I will make it.

I talked to John the other day and told him not to expect any consoling from me seeing that he didn't give it to me – and he agreed – and he shut up. He sent Bea 500 francs for finishing her school year so well, and although I don't think it is right to reward that, I am happy she got some extra money for the sales. I have booked flights for Bea and myself to go to Spain from August 8-18. We (JL and I) won't be going to Canada. Edward is not sure when he want to go for a week with me and a week with his Dad. Bea is happy that Edward will join her when she is with her father and Oxana, from next Monday, July 7.

Entry in my personal diary dated July 21, 2003:

Jean-Luc and I are uneasy about the company situation. I feel that I should know what is going on, that I am going to have to work to reimburse his debts and will have nothing to show for it. Trust, trust.

Entry in my personal diary dated July 23, 2003:

I had a dizzy spell this morning at work. It didn't seem to finish. Marlise and Liselotte came to my help. It was like a panic attack. Ozan drove me home and I slept most of the afternoon. There's a drink at work tonight to say goodbye to the first employee to leave.

Entry in my personal diary dated July 29, 2003:

Three days at home doing my second assignment. Two days in the chalet – one day raking the hay and Sunday spent resting and sleeping. Get back to work yesterday and find myself in a bitch of a bad mood. Found myself angry for doing something for Jean-Luc whereas I've asked him for ages to change my e-mail address and he hasn't. It gets me so peeved that I'm such a

“good little soldier” and he does what he wants, when he wants. I need to learn how to put limits and ask for what I want/need. I think I’m on my way, but I get so angry!

Entry in my personal diary dated August 19, 2003:

I come back from vacation in Spain and I can’t sleep. I’m all fired up at 3:39 a.m. and I’m up doing things.

Entry in my personal diary dated August 25, 2003:

I hit the scales at 71.6 kilos like last summer. I need some kind of motivation to start dieting again. I can’t seem to find it, not like my motivation to clean up the apartment and get stuff sorted out. I’ve done quite a good job on that and Jean-Luc has shown some interest and helped me after I repainted the room. So how do I find the resources to diet, to take care of myself?

Entry in my personal diary dated October 20, 2003:

Edward crisis again! I have dreams full of people all doing different things. I feel kind of out of control. It’s hard work to hold it all together. Three weeks of non-stop training.

Entry in my personal diary dated Thursday, October 23, 2003:

Edward is back in hospital waiting to go to the Institut Maieutique. Jean-Luc bought Bea a ticket to go away on Saturday.

I am starting to calm down and relax with Jean-Luc. He has been in for supper on the last two evenings and has cooked. A difficult week is almost over. 3 days of headache.

Entry in my personal diary dated October 27:

I am profoundly angry, but it isn’t a destructive anger. I am doing things for myself.

E-mail from my father on November 2, 2003:

How is everything? Mark tells me that Edward's news is not good but didn't elaborate which perhaps is best for us. I don't know really but if we are to do the only thing we can do (which is to hold you all in our hearts) then we do need some filtered news?

E-mail to my father on November 8, 2003:

Edward got kicked out of the foyer where he was living. The foyer's director had left and the people working there started doing some strange things, i.e. they were no longer following procedures and there were all kinds of fighting going on. Edward was their victim. It was true that he wasn't in the right place and he was proceeding with his entry into the Institut Maieutique in Lausanne. However, they gave him a rough ride and JL threatened them with legal action so they said he didn't have to leave. He had planned to go to his Dad's and was about to leave, and then they wouldn't let him out. He got really upset and picked up a knife. So they called the police and the police called the doctor (who had said in the afternoon that Edward did not need to be hospitalised in a psychiatric ward) and the doctor said, 'well, if there is nowhere else for him to go, put him in the psychiatric ward.' And the people at the Foyer were all happy until they found out that JL has taken legal action against them ...

So Edward has been back in the psychiatric ward on voluntary entry basis. And John had been terribly upset and wanting to save his son (at least in words). So Edward checked himself out and went up to his Dad's who called me after a couple of days to say he and Oxana can't take it. So I said that he had to take care of Edward or find a suitable accommodation for him. During this hospital time, Edward and John carefully ignored JL, so then he carefully ignored them. In the meantime, Edward's social assistant has changed and the new one told him to tell me that he doesn't want to be pushed into going to the Institut Maieutique if he doesn't want to. Oh yes, and John isn't supervising his medication.

JL says he thinks Edward is bi-polar (because of the ups and downs) and he checked out his medication. All the indications on Edward's medication are for bi-polar depression. Someone is not telling us all. We have called it, when Edward is up, this "I am almighty, I'm so powerful" trip. It has usually started with someone defending his rights and then he becomes impossible for the people looking after him. E.g. John ranted at a meeting at the end of August that his son wasn't being taken care of and he would sue them. After that Edward was so impossible that the foyer said they couldn't take it anymore.

So he's relatively safe. I have had a tough discussion with him, which is what I told Mark about, about his lack of school knowledge and low ability to learn, and his mental fragility which makes it impossible for him to go to a normal

school. I told him that even if I had not used the words before, he had to know that I agree with the doctors that he is mentally retarded and mentally ill. I don't want to talk like that, but I realized that he is pretending that he is not having difficulties. JL also told him last night that he is not coming to live here with us, that his place is in an institution and that he can fart about for a while, but he will end up in an institution – and he can choose to go to a good one, like the Maieutique, or get stuck in a bad one. As for John, I told him not to talk to me cause I don't care to listen.

I don't tell you because it is a never-ending story. We have to learn to ride the waves. Hearing about it cannot always be easy.

I'm looking after his dental care. He has to have about 7'000 francs worth of treatment. He started two weeks ago. It will be mostly paid for by the social services and JL will split the rest between John and me. Lots of love – see you next week.

Letter from my mother – undated – around November 16, 2003:

Dearest Kate – I kept thinking in a moment I shall say “Thank you” for my present – and the moments passed. Moments have a way of doing this sort of thing these days. So I do thank you.... And thank you for inviting us down and the lunch

It was good to talk about Edward. It may seem we are very detached, but we do think of you often and our hearts are with you. When I said, “Parents who do their best shouldn't feel guilty” but the order is that parents often do feel guilty and the feelings rise and fall. Sometimes one copes. Then some small incident or word can trigger the roller coaster. I hear what JL says, but how can we do anything but our best, even if it doesn't work out.

I hope that JL realizes that we do acknowledge his support and caring towards Edward and yourself. For all sorts of reasons sometimes we fail to tell people what we feel and fail to say it at the right moment. We do acknowledge all that he does.

During this time I got into a conflict with my sister and brother. We had planned to meet up around Christmastime in December.

Entry in my personal diary dated November 24, 2003:

The Collingham flat (reserved for December in London) is cancelled. I cancelled it. Evy says I must be nuts to want to go to London.

Entry in my personal diary dated November 25, 2003:

Beatrix wants to go to London.

Entry in my personal diary dated November 29, 2003:

I'm so fed up at doing what others think I should do, that there are times and days for events, like working hard.

Entry in my personal diary dated December 3, 2003:

Session with Evy about the family conflict.

I have a need for family closeness.

I don't like certain values. We have a history of rigid family roles and values.

I do hold beliefs about respect amongst ourselves, about parenting.

I do have the ability to make friendships.

Entry in my personal diary dated December 13, 2003:

It was/is getting a bit tough this week. Getting or trying to get my university assignment done and not succeeding within the amount of time I'd given myself was frustrating. Not finishing the course preparation was frustrating too.

I'm working so hard.

I'm trying so hard.

I want to be able to show I can.

I'm strong and capable.

You don't recognise my hard work.

I deserve more money for such hard work.

I'm the best, the hardest worker. I should be admired.

A little tapping. A relaxation. A visit to Jakob and Anya to set up the workload.

Copy of a document "letter of consent for an assessment from the tutor", dated December 4, 2003, from the Geneva University Hospitals (HUG), Department of psychiatry, Psychiatric unit of mental development (UPDM)

Declaration of consent

Subject: Psychological assessment

As the legal representative (father, mother, guardian) of Edward, I, hereby, accept that a psychological assessment is undertaken by A.M. and S.S.,

psychologists, according to the conditions that have been explained to me. I acknowledge that I can be informed verbally of the assessment result and that upon my request, I may receive a written summary. However, I take note that no information concerning the diagnostic may be given to me, subject to legal provisions of confidentiality and consultation of the medical records.

Signed: Jean-Luc

Legal basis:

Law K180 concerning the relationship between health professionals and patients)

Art. 4 confidentiality

Art. 4A respect of diagnostic

Art. 5 consent

Law K 125 concerning the regulations of people with mental illnesses and the surveillance of psychiatric establishments

Art. 9 al. 3 medical reports: consultation by patients

Law K 2 05 concerning public medical establishments

Art. 17 C al. 6 concerning competence, Commission of surveillance of medical activities – confidentiality – al. 3 in fine

2004, the year Edward moves into his own flat

Entry in my personal diary dated January 19, 2004 at 5 :45 a.m. :

Haven't slept well. Edward was here for supper and he and Beatrix argued and hit each other. He got angry with her because she didn't come to the table because she was on the phone. Last time we spent the weekend together he got mad when we went sledding and he threw a sled at her. I have to ensure that she is protected. I am so scared.

Entry in my personal diary dated Friday, February 27, 2004:

Tired. Dr. B.H.. did get a copy of the PRS blood test. He says that my body “ is speeding on the highway and trying to brake at the same time”. Potential collapse on its way. Slow down – no more speeding. It feels like I'm programmed to run and I can't stop.

Entry in my personal diary dated March 28, 2003:

Tears for I don't really know what. Edward stole money from me. I'm tired. What's new?

Entry in my personal diary dated April 3, 2004:

I have dreamed the past three nights and although I don't remember much I'm glad I'm dreaming again. The doctor says I'm not so badly off, but that I'm tired. Tired because I don't recuperate while sleeping – because I don't sleep long enough – because my body does not eliminate the toxins. I have come down on the scale of developing illness from 4 to 2, out of 6. He has changed my food supplements.

E-mail to my sister on November 20, 2004:

Edward has moved into his own studio flat which represents quite a challenge for him. He is being reassessed by the mental development service and we hope that they will put a learning program together for him to help develop his weaker cognitive capacities. He receives a fair amount of state aid and has it doled out in small amounts by Jean-Luc who administers it all. He lacks for nothing except what nature hasn't given him.

Jean-Luc and I were invited with Edward to attend a session with Mr. M., psychologist, at the Unit for Mental Development. There was also the head of the unit, a psychiatrist. Edward was very nervous about the meeting and arrived a little late. There were five of us in the small office. They read out the report to us and told us that according to their assessment, Edward had an IQ of 75. Edward asked Mr. M., whom he seemed to trust, whether he was 'normal', and Mr. M. confirmed that he was. Edward then got up and said that he had to go out for a cigarette. He was away for about half an hour, and the psychiatrist told us that he admired our calmness, that we didn't run out after him. We discussed what the unit could offer Edward. I had hoped that they would be able to help him with his learning difficulties. The psychiatrist said that they could offer group psychotherapy. I said to him that we could ask Edward if he wanted to do that, but I doubted that it would be helpful. I asked him if they used Cognitive Behavioural Therapy, because Edward had never tried that. He said that they didn't provide that. Edward came back. He had been back to his apartment and changed his clothes. He said that he didn't want to attend group psychotherapy, that he didn't want to take any medication of any kind, and that he didn't like psychologists. We all smiled and said goodbye.

2005, the year life became boring again

E-mail to Jenny on July 1, 2005:

Bea passed her finals and went off to Club Med for a week with her best friend, Sabrina, and family. I went to Paris for two days - one day to work and one day to visit on my own. I am starting to calm down and take life easier. Like today I am not working very hard ...

Edward was supposed to go and see a doctor and "forgot" to go. He is complaining that he will never go anywhere or achieve anything, and he never takes the help that is offered to him. Part of his problem is that he will not take hormonal replacement therapy - he does not produce testosterone naturally - and so he is stuck in a boy's body. He has not had his puberty so he does not shave and his voice has not broken. So he is like a difficult adolescent. It wouldn't be too difficult if he did not tell people he is 20. If you think he is 15, there is no problem. You think what a fun 15 year old - all he wants to do is roller skate. If he took hormonal replacement therapy he would start to become a man. But can you imagine if when you were a girl someone told you you had the choice to stay a girl or become a woman? Do you remember being amazed at your body, or scared or interested about the hair growing under your arms or between your legs, or your breasts and hips getting bigger and curvier? It would be scary to have the choice of saying "no, I have decided to not grow up. I will stay as I am." and then you see all your friends changing. That is what happened to Edward when he was just 16. He already had mental difficulties at school - he cannot do division in maths, but he can do multiplication so he was stuck in 7th grade for three years! And as everyone thought he was just lazy he was criticised so much that by the time he found out he was different physically, he also felt he was useless and stupid. He was hospitalised for depression in the summer of his 16th year (2001) and he has been unable to go back to school since then. From September 2001 he went to a special day center for adolescents with psychological difficulties and was living at home but he became more and more difficult. In May 2002 I broke down and was put into hospital for a couple of days, and he was sent to a foyer for boys but he didn't stay there at night. So after a week they kicked him out and he went to live with John in Fribourg. He was given two jobs and he wouldn't work so he lost both jobs. Then he started running away from his fathers and going to stay with his girlfriend. His girlfriend's family is very rich and they took care of him until her father took legal action against him and he was put in prison for a week. He

was in and out of his girlfriend's house and his father's house until February 2003. Then she broke up with him and he tried to kill himself. He was put into psychiatric hospital and ran away a month later and tried to kill himself again. He stayed in hospital until July 2003 and then he was allowed to go to an adult foyer. He got himself kicked out in October and then was put in a bed-and-breakfast hotel near the skate park and he lived there for a year until we found him a studio in November 2004.

It has been heart-breaking for me to see all of this happen and to feel so helpless and useless. I also became really scared of him and the mixture of fear and guilt (why did I give birth to this poor child?) nearly drove me crazy. I think if I was not such a positive person I would not have survived. For Bea too it was so difficult. She is still quite easily angry with him.

Now we see him a couple of times during the week. He comes for supper regularly. He calls me when he is sad and he cannot cope. He takes absolutely no medication. The doctors worry about him but he won't go to see them. His teeth are almost rotten but he won't go to the dentist. I call him a couple of times a week and he is happy that his Mum loves him. There is a lot of tension between him and John. I don't listen to John on the subject of Edward because I am not his waste-paper basket for his emotions. Jean-Luc is Edward's legal guardian and we provide a certain amount of stability and continuity for him.

The name of his syndrome is Klinefelter - you can do a web search for information. Biologically he is XXY - instead of XY. Girls are XX. You and I know he is a boy, he looks like one, he acts like one. He didn't grow breasts like some Klinefelter sufferers do - what a relief. For a while he wondered if he was gay so he tried that and he decided he preferred sex with girls so he is not gay. He's Edward. He is very likeable and affectionate. He doesn't get angry so much anymore because I told him I don't want to have to deal with that.

There you go. I wanted to wait until we had got more into contact before telling you about it. I don't expect much from him now, but I think it is so sad - especially when I compare what Bea can do with what he can. I think that that is unfair. God didn't give him a fair deal. Shit happens, as the saying goes. I think he will most probably be around in October. I somehow don't see him going to China but he needs a dream.

Love, Kate

Appendix C Re-membering Edward

The stories, or letters, are posted here in order of reception in February 2012.

From Margot

Dear Edward, I remember the first time I saw you. I was sitting at the kitchen table in mom's apartment. You came in, greeted me rather shyly, but ever so properly. I think you even shook my hand! And I thought: "My word, but Kate has an attractive son!" You did not stay long before you breezed out again. After this my chronology of our interactions become a tad muddled, but the memories are very clear, so let us just go with what I remember and not about the when, OK?

The next time I saw you (I can't remember the dates, but that is not that important, is it?), mom was not home when you came by. I was in your, my and Batty's room when I heard you coming in. We met in the foyer and went to the kitchen where you made me a cup of tea. I can so remember thinking how lucky my friend Kate is to have such a well-mannered son. We sat at the kitchen table drinking our tea. Our conversation was about this and that as we were still really just getting to know each other, but I remember quite clearly how you told me about riding your bicycle in Geneva and how some drivers were just plain rude towards cyclists and often caused them to have accidents. I can remember wondering whether you thought of yourself as brave because I sure as anything thought that you were by what you were telling me. And the speed you go at? Ach! My heart would pop seeing you. I would be *so* fearful for you.

Do you remember when mom and I came down to that bar where you worked and you served us? I was so totally impressed by our waiter. He looked so in control of the situation, so smart, so relaxed and so knowledgeable. I was so struck by the sense of calmness you moved about with. It sure seemed as if nothing could ruffle your feathers. I felt so proud when you also gave me a hug good bye. And I was glad to hear that you had stepped away from that situation where it sounded to me like you were being abused. You seem to have this ability to keep on keeping on. When something doesn't work out for you, you move on to the next thing and that is that. Very little fussing.

On another occasion, I was in the sitting room when you came by and we had more tea, which you had made – you are a goodest tea maker!!! And you showed me your new bicycle. You were so proud of it. Do you know that I still have those photographs that I took of your new baby? I had the photo of the sticker on the pipe-thing that holds your saddle as my screensaver on my iPhone!!!! People thought I was the coolest and I could tell them about this guy I know in Geneva that rides like the wind and doesn't even have brakes on his bike. Ach, my heart!

You know, Edward, coming to think of it, I think you take pleasure in making me hold my heart!!! Remember when you took mom and me down to the lake and showed us the tricks you had already mastered on your bike? At times I had to look away because I thought I was going to faint with fear of you falling, but, oh no, the boy just kept going. You sure are a master at riding that bicycle of yours with such control and such persistence. You practice and practice until you get it right. I wonder if you do this with other things, too? Be sure to tell be about them when next I see you. But, then, we normally have so much to talk about that we won't get to remembering about that!

One evening we all had supper together and someone said something that did not sit well with you. I did not know exactly what as my French is a bit rusty (duh!!), but you did not make a scene, you got up, said you were leaving and left. You extracted yourself from a difficult situation in a dignified manner. I learnt a lesson from you that evening. At that time I was having a bit of a thing with someone at work and it often ended up with screaming matches. After I saw you leave, I thought that I would do that next time. I would say: "Sorry, I don't have time for this" and leave. It worked. The screaming at each other stopped and it was much, much better for me because then I did not have to spend so much time getting over my anger.

As time went on and I got to know you better, you started giving me 'hallo' and 'goodbye' hugs. I do love those hugs. It is as if your whole body is saying 'hallo' and 'goodbye'. I feel so special when *my* boy, Edward, gives me a hug. I often tell people about this special young man in Geneva who had invented hugs! What makes this young man special at hugs, is that he is twice as tall as I am, but he still manages not to do hugs awkwardly. I tell people that I will give them your phone number so you can teach them about giving hugs.

And Uncle Joe's party. Ach, Edward, how special was that? At one time you told me that people often freak you out and you have to escape. Well, that weekend I watched you interact with what felt like one zillion people for one whole weekend without even blinking an eye of irritation. Remember that you even stayed on on the Saturday evening sitting around the fire when us old fogies went home? Now, hey, how did you manage to do that when the stories you told me were about you not liking being around so many people for too long? Edward, I wish I had recorded all the people at Uncle Joe's who had said what an amazing young man you were because I have a sense that you are thinking ,right at this minute, that I was making it all up.

And the other day when I spoke to you on the phone and you said that you loved me and missed me I cried. I felt *so* special. So, so very special. Like you are to me. Special. Very, very special.

Edward, there may have been difficult times in your life before and there may be difficult times ahead for you, but I want you to know that I think you are right grand and that I would go anywhere with you and be seen with you at any time. And what makes me feel safe with you is the knowledge that you have experienced some frustrating times in your life, that you have learnt the skills to overcome those frustrations most of the time and when you and I, both, experience frustration, we can find a field somewhere and scream together until our frustrations are all in the wind and we are calm and relaxed and rearing to go again.

But, lastly, boy of my heart, I want to say how blown away I was that day you showed me the XXY tattoo on your arm. Edward, that flies in the face of what most people would do and speaks to me of personal bravery, maturity and acceptance of something you can't change, but that you have learnt to live with. In my life I have seen many, many so-called grownups that can't do that. And that is all I have to say about that, in the words of Forest Gump!

Darling, Edward, may the Force be with you, always and forever! And thank you for being in my life in your very specific way. Muchest love, Margot

From Jenny

I had the privilege of being an au-pair for Edward and Beatrix when they didn't go to kindergarten yet. So, we had the opportunity to do so many nice things together, which of course we did. We used to sing songs, read stories, go swimming in Meyrin, go play at Bois de la Batie, had long walks, play in the garden and so many more things.

To me, Edward was a sweet handsome little boy, who stole my heart from the first moment I saw him. Edward had so much love to give, that he really made me feel special. He was such a nice brother to his sister Beatrix. Of course as every brother and sister, they had their little fights now and then. (nothing compared to the fights my 2 youngest sons have now)

Whenever we do something or go somewhere, Edward was in such a good mood. Never complained that he didn't want to do this or that, or didn't want to come. The smile was on his face and he seemed a happy little boy who had fun. When we went swimming, it was lovely to see Edward and his friend at that time, named Sebastian were showing off. I took so many pictures, and on every photo you can see Edward with this smile on his face. And photos don't lie.

It was so sweet how he called me Johnny instead of Jenny. Of course the story of the fish in the bathtub (which was poo) was so funny. Edward loved being in the bathtub. He never wanted to come out of it. Always tears. I thought I had found the solution by letting the water go away first and then take him out. It didn't help. So I didn't do it again.

There was also the time that he had to let go of his nuggi (pacifier). Kate and I spent several nights near his bed, trying to comfort him. One night I told Edward to try his thumb. It worked ! And of course there was still cushy ! (Soft Cushy was Edward's teddy bear).

I remember fish fingers being one of his favourite meals and risotto. Or maybe that was the only thing I could prepare. I'm still not a princess in the kitchen.

When Edward was a few years older, I came over to Geneva to mind him and his sister for a week. At one point Edward didn't agree with something and told me he would run away and that the wolves would eat him. So, off he went. Not long after that he came back and said I was lucky the wolves didn't eat him. And

yes, I am !! I'm so lucky they didn't eat Edward. So happy that I saw him back as a grown up handsome sweet boy after so many years, when he picked me up at the airport on his skates with Jean-Luc.

I have learned so many lessons of life because of Edward and Beatrix. I still love them with whole my heart even I don't see them as often as I would like to. If I tell you that in my house I have only a few pictures of my children and a photo of Edward and Beatrix. I think that says enough.

From Fiona

Edward, I remember you as a kind and loving boy with a caring heart. It was always a lovely feeling for me to come to your place either in Peney or in Geneva and have an exuberant hug and cheek-bisous from you! It felt as if we liked each other. And I still think so.

I used to feel your frustrations sometimes - maybe quite acutely because I'm a bit like that myself - and your need for freedom which seemed to clash inside you with your need for security. Do you remember we were at Paleo Rock Festival one year with your Mum and Bea? I would guess you were about 11 or 12 years old. Can't remember how or why but you and I were on our own for a while. You so desperately wanted to head off by yourself - which terrified me as there were several thousand people around us and I figured I might never find you again. So I did a tough thing (for me, the respecter of freedom) and held so tightly onto your arm as we got pulled along in the crowd. You were angry as hell and wriggling like crazy but I stopped and said, "Edward, we stick together. We're on our way to see an act I want to see because it's on first. Then we'll go and see the band you want to see - because it's on next. OK?"

You looked right at me, still angry, and considered. You were a strong boy and could easily have wrenched away and disappeared into the crowds. I don't know what you thought on that moment but possibly you understood and responded to my fear. Then you said "OK" and I knew I could trust you. I recall you hated the singer I wanted to hear and I was not that enamoured of your band either :-)) but we stayed together, had a few laughs and I was able to meet up with your Mum with the sense of relief that we had not lost each other and above all no harm had come to you. Thank you for that!

From Françoise

Une fin d'après-midi ensoleillée, j'étais allée faire une pause entre 2 cours au bord du Rhône près du BFM : il y a là une roulotte-café sympa, des chaises-longues et une ambiance assez « cool » et assez « jeune ». J'ai connu Edward garçon, puis adolescent et je ne l'avais pas ou peu revu depuis. Il était là avec une bande de copains et je lui ai fait un petit signe de loin - du genre : la-vieille-copine-de-ta-mère-te-voit-mais-ne-veut-pas-s'immiscer... Edward s'est levé, est venu vers moi tout souriant, m'a fait la bise super gentiment, m'a demandé si j'allais bien et si je venais souvent par là.

Ce jour-là, j'avais quelques soucis et Edward ne le savait certainement pas, mais il m'a fait énormément de bien ! Ce fut un très beau moment pour moi, avec la lumière de cet après-midi et ce grand gaillard qui quitte ses copains pour venir me saluer.

From Cathryn

I have very fond memories of my time as Au Pair to Edward and Beatrix when they were 7 and 5.

The soundtrack to that time was my Queen tape! I was given it by a friend before I left for my Swiss Experience. On countless occasions we sang on the top of our voices while driving the winding road on the school run. For many of these trips Edward was half hanging out the window of the Golf singing away. Our favourite song was Good Old Fashioned Lover Boy, but known as 'oo love'...the first words of the chorus. One of the most poignant moments of my wedding 9 years later was dancing with Edward to that song, oo love, just the two of us on the dance floor singing along with pure joy.

He always was and remains one of the most charming men I have ever met.

From Mary and Zion

Here is a story from Zion who often talks about his day on the slopes with dear Edward: Hi love, Voilà ma journée de ski avec Edward à Villard, il y a environ 8 ans. On est parti skier Kate, Edward, Béatrix et moi. C'était la première fois que j'ai skié à Villard et Edward a tout le temps surveillé que j'ai suivi l'équipe et que j'allais bien. Il s'est énormément amusé en skiant. Il skiait très bien - il faisait des sauts partout où il pouvait. Quand on est allé boire une boisson chaude dans un bistrot il riait et cherchait bien à me faire rire. J'ai passé

une magnifique journée de ski à sa compagnie. Je trouve qu'il est une personne très généreux et plein de vie.

De ma part, Kate j'ai aussi toujours eu des expériences positives en compagnie d'Edward et trouvais qu'il est charmant, attentif et beau.

From Patricia

Je n'ai pas eu l'occasion de côtoyer Edward très souvent, mais ce que je peux te dire c'est que quand je suis venue à ton appartement la dernière fois que j'avais une répétition avec la comédie musicale, j'ai trouvé Edward très attentionné et vraiment adorable. Il m'attendait chez toi, m'a donné la clé, m'a tout bien expliqué pour le chat et Il m'a encore envoyé un sms le lendemain pour me demander si tout avait bien été, aussi avec le chat, et j'ai trouvé ça vraiment sympa. Voilà, c'est peu, mais je voulais témoigner de sa gentillesse

From Elizabeth

Edward and I. Who said chivalry was dead?

Geneva, rue Ami Lévrier, 15, a while ago. My apologies to those who like to have specific dates. I don't think it's important for this story. Time goes so fast at my age that the expression "a while ago" can in fact mean anything from yesterday to years back. Now, I don't usually say things such as "at my age" because I don't feel "my age" but I think it's important for this story.

And why is it important for this story? Because at dinner with Kate, Edward and possibly Jean-Luc (sorry JLS, I can't remember if you were there) Edward and I are having a great conversation and I appreciate the way Edward seems to enjoy talking with a lady who is older than his mother, which is not the case of a lot of young people. I can see from his eye contact that he is totally engaged in the conversation and we are having a good laugh. He is animated and articulate and funny.

So this is great, but all good things must come to an end and it is time for me to take my leave. Edward also has to leave and so we take the lift together. At the door to the apartment block Edward opens the door and holds it open for me to go through first. He recommends me to "take care". I feel respected and protected. Edward, you're a gentleman...

From Daniel, written by Elizabeth

Edward et Papé font du ski...

Edward mesure 1m90 et pèse 67 kilos. Edward est suisse et anglais. Il avait 24 (?) ans au moment de cette aventure. Daniel mesure 1m68 et pèse 76 kilos. Il est français avec un bel accent du Midi. Il avait 66 ans au moment de cette aventure.

Nous sommes à Huémoz, vieux village situé dans le canton de Vaud et fief des Lindley-S. depuis quelque ans. Le chalet Lindley-S. est un des plus anciens du village. Il y fait bon vivre et il y fait très bon manger. Si j'ajoute ces détails ce n'est point pour flatter l'ego du maître des lieux et accessoirement excellent cuisinier mais pour mieux planter le décor de notre histoire.

Nous sommes en hiver, vraisemblablement un samedi. Daniel et moi sommes invités à souper et avons prévu de dormir sur place. C'est plus prudent vu ce que nous allons sans doute manger et boire. Edward nous fait l'honneur de se joindre à nous. Le repas est excellent et le vin délicieux et copieux. Il est même fort possible que nous ayons terminé avec un petit whisky. Nous avons bien fait de choisir de dormir sur place car nous sommes tous - comment dire? - un peu fatigués...

A tel point que, le lendemain, quand Daniel veut absolument aller skier, il ne trouve personne pour l'accompagner – sauf Edward... Et là, si vous avez été attentifs aux détails donnés en début du récit, vous vous ferez une jolie image du duo de skieurs. Un grand jeune longiligne, en tenue de “boarder” et un monsieur d'âge respectable, plutôt bien portant et en tenue classique de skieur moyen. Ni l'un ni l'autre ne voient cette disparité et c'est ça qui est beau.

Les voilà joyeusement partis en fin de matinée. Quand ils reviennent, ils sont détendus, complices, contents d'eux et de leur journée. On ne saura pas exactement s'ils ont dévalé ensemble d'innombrables pentes vertigineuses mais on apprend qu'ils ont très bien mangé. Après tout, c'était le plus important! Merci, Edward d'avoir accompagné Daniel et m'avoir permis de me remettre gentiment de ma soirée!

From Beatrix, Edward's sister

This exercise is very difficult as I have so many memories of my brother Edward. As I am the closest being to him (we share the same blood), may I be allowed to share two of them? One childhood memory and one adult one.

The childhood one is about when we used to travel to England in the summer to stay with Gran and Grand-dad. We used to take the plane as "unaccompanied minors" and Edward was always talking to everybody, passengers, stewards, hostesses and so on. He was so outgoing and outspoken and made friends everywhere in such a short time. Then, he always wanted to introduce me to all of them saying: "and here is my sister Beatrix". I was so proud of being his sister and happy to be included. He would never let me out of anything; I was always welcome to join in. I loved his smell too, I remember falling asleep against him in the plane and his smell would reassure me.

The second memory I choose happened just the other day. He came over to see me and brought some sandwiches and cookies from his favorite place- he even made me a cup of tea. We had a lovely moment sharing the last developments of our lives around the kitchen table. Very often, I get the feeling that he wants to be with me and talk. Before he leaves, he always takes me in his arms and tells me he loves me.

I can see deep through my brother's eyes: his sorrow, his joy, his yearning for love and recognition. And actually, what I love the most about him is that he can see right through me too. We are each other's mirror.

From Christopher / Edward's grand-dad

Alas, my memory is not what it used to be so I spent an hour or so looking through our 1985 - 88 photo albums for Edward as a child. There were many photos from Lens and Geneva and they reminded me that he was a happy child - he is smiling or laughing in most of the photos. Many happy photos of him with you or John too.

I have some good memories of him on the ski slopes too. We spent many days skiing with you and your kids, and he was on his snowboard whilst we were on skis. He was pretty fearless with a bit of a devil-may-care attitude but really happy. There were many good days together on those holidays.

Another comment is that he has always been polite and courteous to us - and goodness knows I was not always very loving to him. There are memories of difficult incidents when he stayed with us when I was not very understanding or tolerant of him.

I also remember having a meal in a McDonalds near Geneva Station after he had moved into his apartment when we talked about all sorts of things. These are just a few thoughts about one of our great grandchildren.

From John / Edward's father

The Swiss town of Geneva is situated at the end of a large lake. The city is formed around a natural bay in which several hundred boats anchor on the first week end of August to watch a spectacular firework display. Hundreds of thousands of spectator mill around the waterfront, but it is from the deck of a boat that one can has a really immersive experience of the show. Our boat was moored in a French town some 30 nautical miles from Geneva. Edward, Beatrix and I decided to go down and join the festivities. Arriving early afternoon is the only way to pick a spot in the front rows of boats therefore we left our mooring at seven that Saturday morning. A very light wind gave us a steady four knots giving us an estimated arrival around half past two. We would only get back to our home port early the next morning since the return trip would take place after the end of the fireworks. Some long sailing hours lied ahead of our crew. Life on board took on its normal routine of cups of tea, biscuits and lazy conversations. I was at the helm for the first four hours until lunch time. Edward offered to take the helm of the boat after lunch, we were going to get into more crowded waters and I was a little apprehensive leaving the responsibility of a 36ft sailing boat to him but I also thought that we had sailed together so much since his childhood that he could manage and that this would be a great opportunity for him to demonstrate his abilities. He insisted I rest, which was a good idea given the long hours we had ahead of us. I went down to my cabin.

The course was set for him and we were in familiar waters. However as one approaches Geneva the lake narrows to less than a mile across with some underwater hazards that must be avoided. In addition, on that day, the traffic becomes intense. My plan was to wake up and take over in the last hour but the jet lag I had accumulated from the week travel to Asia took the better of me and I fell into one of those deep sleeps that an earthquake would not bother. The

strange thing was that I also felt safe with Edward at the helm. This is strange because for a sailor one always is alert to every creak and movement, as if the boat was speaking to you and needed your constant attention.

I was awoken nevertheless by a rattling noise from the bow, it was the anchor chain. Edward had taken us in and was setting anchor in a rather optimal spot. That night on our way back, while both Edward and Beatrix were sleeping tightly below, on a calm moonlit lake, I felt so happy for him. This was our lake, this was his moment of taking control of his destiny, it was important to both of us.

From Ben

I've always had very positive contacts with him. It's not as if I could identify one or two exceptional occasions out of a sea of bad, we've always had friendly relations and I've always been impressed by what a loving and protective son and brother he is.

From Annie-Laure and Denys, aunt-in-law and uncle-in-law

Pour Edward, nous n'avons pas de souvenir précis d'un moment spécial, mais je peux dire pour nous 2, (après discussion) que, lorsque les conditions sont réunies, nous apprécions beaucoup sa douceur, son écoute, sa capacité à aimer. Il exprime toujours du plaisir à nous voir, et ça nous est très agréable. Moments de plaisir aussi lors de partage où Edward se montre très étonnant, ouvert, tolérant.

Pour ma part, je me souviens aussi de moments de discussion très agréables et importantes pour moi. Edward ose parler de ce qu'il ressent et sait questionner et écouter. Il fait partie du petit groupe de gens avec qui j'ai des discussions enrichissantes.

From Berthe

Pour moi, Edward c'est l'homme sur roues ! D'abord petit garçon sur roues qui arrivait, avec ses patins, à monter la pente assez raide jusqu'à mon premier lieu de travail. Plus tard, ado qui traversait la ville en quelques minutes pour arriver à l'heure malgré quelques détours. Plus tard grand ado sur roues dont les roues n'arrivaient plus toujours jusqu'à mon cabinet... parce le parc des skateurs le happait au passage.

Maintenant encore, quand je passe devant ce parc, il m'arrive de regarder si je ne vois pas sa haute silhouette mince en train de faire des prouesses ou de se mélanger aux autres.

Dans ma pratique thérapeutique j'utilise le jeu de sable. Edward en a été un adepte passionné. Mises en scène formidables de catastrophes où un maximum de véhicules était concerné et que, soucieuse, je regardais se construire, avec in extremis quelque engin qui était sauvé... Puis Edward me lançait un dernier clin d'œil provocateur et brusquait mon soulagement en annonçant une catastrophe future. Et le jeu recommençait la fois d'après, avec le même enthousiasme. Bon vent à Edward, je lui souhaite que son habileté physique, son intelligence des autres et son humour l'aident tout au long de sa vie.

From Sheila

While I've never met Edward, I've heard so much about him! And what strikes me most about "Edward-Stories" is what a determined and good-natured person he is. Some of his "good nature" could probably be seen by some as defensive (as in, "Don't worry Mum, it's my body, not yours.") But I hear these stories as stories of resilience crafted in humor and a certain sense of self that allows moving through the world in self-assurance of the best kind. I know Edward as a strong, resilient, amusing young man who is competent and independent. That's the story I've heard!

From Gran

In the summer of 2010 I needed a break, so I set off to stay with Kate for a week. Prior to the journey I decided I needed a new suitcase and decided a red one for easy recognition. I now know how many others thought the same... Eddie met me at Geneva Airport. He was standing there with his bike as I trundled out with my brand new suitcase. Eddie took charge taking my suitcase; we descended the escalator to the booking office. He insisted on paying my fare. So down the next flight of stairs to the platform, Eddie got us all on to the train and came and sat with me chatting. Halfway to town I had an OMG moment. I looked at the red suitcase; it had three zip pockets on the front and mine had two. My heart and mind went blank but Eddie just took over. He got off the train at the next stop, ushered me across to the other platform, with bike and suitcase, and helped me onto the next train back to the airport. Quickly he found the correct office and he stayed outside while I explained to the young lady about my 'senior' moment. If he was embarrassed he braved it well.

Having filled up the necessary forms I emerged with new red easily recognisable suit case, and once more Eddie took over, taking Gran through to ticket office. This time I insisted on paying. We then completed the journey to Geneva, where Eddie left me and I continued to Aigle where Kate met me off the train. What really touched me was that he didn't make fun of me or tease me; it could have made a great story for laughs.

From Judith, honorary stepmother

EuroDisney 1995

I spent 3 days early January in this famous theme park on the outskirts of Paris as a new member of the Niser family. Edward had just turned 10 and Bea was 8 years old. Unfortunately, the latter was not tall enough for some of the rides and since I had never been there before was eager to try out everything possible. So we came to the arrangement that John would stay with Bea and Edward and I would have fun. And we did!! Since it was cold and there was snow on the ground, the queues were not too long and so after having finished a ride we'd run around and go back on. Edward was a brilliant companion - being as caring and attentive as we all know he can be. We would meet up with the others and then run off again for some more adventures. I'll always remember this short holiday with fond memories ... which have nothing to do with Mickey Mouse!

Cayeux-sur-Mer 1995

We were spending a couple of weeks as a family in Picardie and had towed the RIB so as to explore that area of the English Channel. Most days we went off for some trips in the Somme estuary, but rarely made it out to sea. We obviously had to be careful with tides, and planning was needed for a worthwhile trip. So one morning, John, Edward and I left Hubert's house at dawn and made it up the estuary just as the tide was in enough to be able to navigate the Somme. We then motored along the coast-line to Le Tréport getting there just in time to enter the port while there was still enough water. Now we could relax; couldn't move the boat until the tide started coming in again. So we walked around the town and up the hills above the cliffs. When possible, we got back in the RIB and got onto the sea; but this time had to wait for there to be enough water in the Somme estuary. So we drifted out at sea. John was the 'lookout' while Edward and I enjoyed the silence, looking out for dolphins. That was a very special moment I shared with him. The whole day, Edward was great ... despite feeling rather seasick after too much bobbing in the waves.

Peney-Dessous 1997

As Edward got older, his swearing got more unbearable. I realised that telling him off only made the matter worse, yet I felt compelled to find a way to get him to realise what he was saying and how unpleasant it was for those in his company. So, one day, while playing with the Scalextric in the living room together we devised a plan together. Instead of him saying one of the more conventional words to express his discontent, he would substitute them for any word which would be accepted by society. The word he chose was 'voiture'. So each time after that he swore, I wouldn't tell him off, just make a gesture or prompt him verbally to say his special word. This became a game, which was only understood by him and me. It seemed to work for a short while, but I was not consistent enough to have taken it any further. Maybe Edward will be able to coach my daughters in the same way when they start using bad language ... and this time be more careful to make it work.

From Charlotte, Edward's aunt

Dear Edward, your mum asked for remembrances of you growing up. When I sat down to write this I realized that I could probably count on one hand the number of times we have been together.

So I will start with the first time I met you. It was Christmas 1986, you were two years old and Esther and Bea about 3 months. We all came to England for Christmas – Gran and Grandad were still living in New Jersey. You were such a happy blond blue eyed boy. I specifically remember you helping your mother vacuum the living room.

Fast forward to your visit here in the US Christmas 2001. You slept downstairs on the sofa so you could exit quickly for a ciggy. We visited Independence Hall and the Liberty Bell in Philadelphia.

Then there was our visit to Geneva and the chalet in 2002. You were at home so were able to escape when you needed to! Will loved hanging out with you. My next memory of you is after Auntie Hennie's funeral in 2004 and having lunch in a pub – it was warm for April so we sat outside at picnic tables. You and Will played with my cell phone.

These three remembrances are tied up with William. William was diagnosed with ADHD in 1st grade. He had always been a handful pushing the limits until

I would lose my temper. You and William seemed to naturally gravitate towards each other. William is now 19 years old and can point out kids with ADHD – this is the zone he feels most comfortable in – he is still pushing the limits – loves to free ski and hang out with friends. He is full of empathy. I suspect you are the same. Having children, especially a challenging one, gave me the opportunity to learn that human beings come in complex wonderful shapes and sizes and each have a gift to give us as we learn to know them. It is always changing, it never black or white – it is shades of grey. William teaches me to look at life differently. And so this work of your mother's is something for us to treasure because you look at life differently and you are to be treasured. My parting words to you other than be happy, are to value relationships because in the end this gives our lives meaning. Love, Auntie Charlotte

From Jean-Luc, Edward's stepfather

Pas facile de trouver UNE histoire positive, la vie avec Edward depuis 19 ans est une suite de choses anormales, il faut s'attendre à tout, à tout moment, alors dur de se souvenir de quelque chose de particulièrement positif ou négatif.

Chaque fête, chaque voyage est une source de grand stress pour lui et pour nous, et au final cela se passe en général très bien, de mieux en mieux, d'ailleurs et chaque fois il nous en est reconnaissant. Chaque fois il progresse et grandit.

Edward at his best c'est ces instants où l'on oublie, pour un moment, qu'il est différent.

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References

- Adiche, C. (2009). *The danger of a single story*. Transcript available on dotsub.com/view/63ef5d28-6607-4fec-b906-aaae6cff7dbe/viewTranscript/eng Accessed on November 2, 2012.
- Althusser, L. (1971). Ideology and ideological state apparatuses. In *Lenin and Philosophy and other essays*. London, UK: New Left Books.
- Alvesson, M. (2002). *Postmodernism and social research*. Milton Keynes, Bucks: Open University Press.
- Anderson, T. (1991). *The reflecting team, Dialogues and dialogues about dialogues*. New York, NY: W.W.Norton & Company.
- Anderson, H.D. (1997). Collaborative language systems: toward a postmodern therapy. *Conversation, language, and possibilities: A postmodern approach to therapy*. New York, NY: Basic Books
- Atkinson, R. (1998). *The life story interview*. Sage University Papers Series on Qualitative Research Methods, Vol. 44. Thousand Oaks, CA: Sage.
- Badinter, E. (1980, 1981 translation into English). *Mother love, myth and reality*. New York, NY: Macmillan Publishing.
- Bakhtin, M. (1981). Discourse in the novel. In M. Holquist (Ed.) *The dialogic imagination*. Austin, TX: University of Texas Press.
- Baum, S. & Lynggaard, H. (2006). *Intellectual disabilities, A systemic approach*. London: H. Karnac (Books) Ltd.
- Beaudoin, M.-N. (2005). Agency and choice in the face of trauma: A narrative therapy map. *Journal of systemic therapies*, Vol. 24, No. 4, 2005, pp. 32-50.
- Bender, B.G., Linden, M.G. & Robinson, A. (1993). Neuropsychological impairment in 42 adolescents with sex chromosome abnormalities. *American journal of medical genetic (neuropsychiatric genetics)* 1993, Vol. 48, pp. 169-173.
- Bentall, R. (2009). *Doctoring the mind*. London: Penguin Group.
- Berger, P.L. & Luckmann, T. (1966). *The social construction of reality*. Garden City, NY: Doubleday
- Bettelheim, B. (1967/1972). *The empty fortress: Infantile autism and the birth of the self*. New York, NY: Free Press.
- Bettelheim, B. (1987). *A good enough parent*. London, UK: Thames and Hudson Ltd.

- Blaffer Hrdy, S. (1991). *Mother nature: Maternal instincts and how they shape the human species*. New York: Ballantine Books, Random House.
- Bly, Robert (1991). *Long John: A story about men*. UK: Element Books.
- Boscolo, L., Cecchin, G., Hoffman, L., Penn, P. (1987). *Milan systemic & family therapy: Conversations in theory and practice*. USA: Basic Books, Perseus.
- Bourgois, P. (2002). Respect at work: 'Going legit'. In Taylor, S. (Ed.) (2002). *Ethnographic Research: A Reader*. London, UK: Sage.
- Breggin, P.R. (1998). *Talking back to Ritalin: what doctors aren't telling you about stimulants for children*. Monroe, ME: Common Courage Press.
- Bromley, J., Hare, D.J., Davison, K. & Emerson, E. (2004) Mothers supporting children with autistic spectrum disorders. *Autism*, December 2004, Vol. 8, No. 4, pp. 409-423.
- Brown, J. (Ed.) (2005). *The world café: Shaping our futures through conversations that matter*. San Francisco, CA: Berrett-Koehler.
- Bruining, H., Swaab, H., Kas, M. & Van Engeland, H. (2009). Psychiatric characteristics in a self-selected sample of boys with Klinefelter syndrome. *Pediatrics*, 2009. Retrieved from paediatrics.aapublications.org on September 28, 2011.
- Bruner, J. (1991). Self-making and world-making. *Journal of Aesthetic Education*, Spring 1991, Vol. 25, No. 1.
- Buber, M. (1970). *I and thou*. New York: Charles Scribner's Sons.
- Burke, I. and Stets, J. (2009). *Identity Theory*. Oxford, UK: Oxford University Press.
- Burkitt, I. (1991). *Social selves, Theories of social formation of personality*. Thousand Oaks, CA: Sage.
- Burr, V. (2003). *Social constructionism*. London: Routledge.
- Butler, J. (1990). *Gender trouble*. New York, NY: Routledge.
- Butler, J. (2004). *Undoing gender*. New York, NY: Routledge.
- Butler, J. (2005). *Giving an account of oneself*. New York, NY: Fordham University Press.
- Campbell, J. (1972). *Myths to live by*. New York, NY: Viking Press.
- Carpenter, L. & Austin, H. (2007). Silenced, silence, silent: Motherhood in the margins. *Qualitative Inquiry*. 2007, Volume 13, pp. 660-674.

- Charmaz, K. (1995) The body, identity, and self: adapting to impairment. *The Sociological Quarterly*, Vol. 36, No. 4, pp. 657-680.
- Chase, N. (2011) Narrative inquiry: Still a field in the making. Denzin, N.K. & Lincoln, Y.S. (Eds.) (2011). *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.
- Châtelet, N. (2002). *La tête en bas*. Paris, France: Editions du Seuil.
- Chua, Amy (2011). *Battle hymn of the tiger mother*. London, UK: Bloomsbury Publishing Plc.
- Cigno, K. & Burke, P. (1997). Single mothers of children with learning disabilities: An undervalued group. *Journal of interprofessional care*, 1997, Vol. 11, Nr. 2, pp. 177-186.
- Clandinin, D. J. (2007). *Mapping a methodology*. Handbook of Narrative Inquiry. Thousand Oaks: Sage.
- Cobley, P. (2001). *Narrative*. Oxon, UK: Routledge.
- Cooperrider, D. (1990). Positive imagery, positive action: The affirmative basis of organizing. Srivastva, S., Cooperrider, D. & Associates (Eds.) *Appreciative management and leadership*. San Francisco, CA: Jossey-Bass.
- Coué, E. (1990). *La méthode Coué, La maîtrise de soi-même par l'autosuggestion consciente*. France : Marabout.
- Crotty, M. (2010). *The foundations of social research: Meaning and perspective in the research process*. St. Leonards, Australia: Allen & Unwin.
- De Beauvoir, S. (1949, 1972 translation into English). *The second sex*. Harmondsworth, UK: Penguin Books Ltd.
- DeCecco, J.P. & Elia, J.P. (1993). *If you seduce a straight person, can you make them gay? Issues in biological essentialism versus social constructionism in gay and lesbian identities*. Binghamton, NY: Harrington Park Press.
- Dekker, S. (2012). *Just culture: Balancing safety and accountability*. Hampshire, UK: Ashgate.
- Denzin, N. (2003). *Performance ethnography: Critical pedagogy and the politics of culture*. Thousand Oaks, CA: Sage Publications.
- Derrida, J. (1972, 1981 translation into English). *Positions*. Chicago, IL: University of Chicago Press.
- Diamond, M. & Sigmundson, H.K. (1997). Sex reassignment at birth: Long term review and clinical implications. *Archives of paediatrics and adolescent medicine*. March 1997, Vol 151, pp. 298-304.

Diamond, M. & Beh, H.G. (undated) *The right to be wrong: Sex and gender decisions*. Retrieved from <http://www2.hu-berlin.de/sexology/BIB/DIAM/right.htm> on September 28, 2011.

Diamond, M. (2000). Sex and gender: same or different? *Feminism & Psychology*. 2000, Vol. 10, Nr. 1, pp. 46-54.

Diamond, M. (2002). Sex and gender are different: Sexual identity and gender identity are different. *Clinical child psychology and psychiatry*. July 2002: Vol. 7, Nr. 3, pp. 320-334.

Diamond, M. & Watson, L.A. (2004). Androgen insensitivity syndrome and Klinefelter's syndrome. *Child and adolescent psychiatric clinics: Sex and Gender*. 2004, Vol. 13, pp. 591-607.

Dillon, J. (2011) The personal is the political. In Rapley, M. Moncrieff, J. & Dillon, J. (Eds.) (2011). *De-medicalizing misery: Psychiatry, psychology and the human condition*. Hampshire, UK: Palgrave Macmillan.

DiQuinzio, P. (1999). *The impossibility of motherhood: feminism, individualism and the problem of mothering*. New York, NY: Routledge.

Dixon, N.M. (1998). *Dialogue at work*. London, UK: Lemos & Crane.

Dreger, A.D. (1998). *Hermaphrodites and the medical invention of sex*. Cambridge, MS: Harvard University Press.

Du Gay, P., Evans, J. & Redman, P. (Eds.) (2000). *Identity, A reader*. Thousand Oaks, CA: Sage.

Dyson, L.L. (1996). The experiences of families of children with learning disabilities: Parental stress, family functioning, and sibling self-concept. *Journal of learning disabilities*. May 1996, Vol. 29, No. 3, pp. 280-286.

Dyson, L.L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American journal on mental retardation*. June 1997, Vol. 102, No. 3, pp. 267-279.

Eichenbaum, L. and Orbach, S. (1983). *Understanding women*. London, UK: Penguin Books Ltd.

Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of intellectual disability research*. January 2003, Vol. 47, Issue 1, pp. 51-58.

Elias, N. (2000). *The civilizing process*. Malden, MA: Blackwell Publishing.

Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: Altamira Press.

- Emmons, R.A. & McCullough, M.E. (Eds.) (2004). *The psychology of gratitude*. New York, NY: Oxford University Press.
- Epston, D. (1999). Co-research: The making of an alternative knowledge. *Narrative therapy and community work: A conference collection*. Adelaide, Australia: Dulwich Centre Publications.
- Eugenides, J. (2002). *Middlesex*. London, UK : Bloomsbury Publishing Plc.
- Evison, R. & Horobin, R. (1988). Co-Counselling. In Rowan, J. & Dryden, W. (Eds.) *Innovative therapy in Britain*. Milton Keynes, UK: Open University Press.
- Evison, R. (1990). *Encouraging Excellence in Trainer Classroom Delivery*, Research report to the European Educational Services Division of Digital Equipment. Pitlochry: Change Strategies.
- Evison, R. (2006). Changing to learning cultures that foster lifelong learners. In Sutherland, P. & Crowther, J. (eds) *Lifelong learning: concepts and contexts*, pp.94-107. London & New York: Routledge.
- Faludi, S. (1991). *Backlash: The undeclared war against women*. London, UK: Vintage.
- Floyd, F.J. & Gallagher, E.M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behaviour problems. *Family relations*. October 1997, Vol. 46, No. 4, pp. 359-371.
- Foucault, M. (1969, 1972 translation into English, 1989). *Archaeology of knowledge*. London: Routledge.
- Foucault, M. (1973). *The order of things: An archaeology of the human sciences*. New York, N.Y: Vintage/Random House.
- Foucault, M. (1978/1980/2010) *Herculine Barbin*. New York, NY: Vintage Books Edition.
- Frank, A.W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.
- Frank, A.W. (2005). What is dialogical research and why should we do it? *Qualitative Health Research*. September 2005, Vol. 15, No. 7, pp. 964-974.
- Fraser, H. (2008). *In the name of love: Women's narratives of love and abuse*. Toronto, Ontario: Women's Press.
- Fredman, G. (2004). *Transforming emotion: Conversations in counseling and psychotherapy*. London: Whurr Publishers.
- Freedman, J. & Combs, G. (1996). *Narrative therapy: The social construction of preferred realities*. New York, NY: W.W. Norton & Company.

- Freud, S. (1933). *New introductory lectures on psycho-analysis*. London, UK: Hogarth.
- Fruggeri, L. and McNamee, S. (1991). Burnout as social process: a research study. *New systemic ideas from the Italian mental health movement, Systemic thinking and practice series*. London: Karnac Books.
- Gale, J. (1992). When research interviews are more therapeutic than therapy interviews. *The qualitative report*. Fall 992, Vol. 1, No. 2.
- Gergen, K.J. (1991). *The saturated self*. USA: Basic Books, Perseus.
- Gergen, K. (1994). Self-Narration in Social Life. Wetherell, M., Taylor, S. and Yates, S.J. (Eds.) (2001) *Discourse theory and practice*. Reading 18, pp. 247-260. London,UK: Sage.
- Gergen, K. J. (2008). Therapeutic challenges of multi-being. *Journal of Family Therapy* (2008) Vol.30, pp. 333-348.
- Gergen, K.J. (2009). *Relational Being, Beyond Self and Community*. New York, NY: Oxford University Press, Inc.
- Gergen, K.J. (2010) The acculturated brain. *Theory & Psychology*, 2010, Vol. 20, Nr. 6, pp.1-20.
- Gergen, K.J. and Gergen, M.M. (1988). Narrative and the self as relationship. L. Berkowitz (Ed.) (1988). *Advances in experimental social psychology*. New York: Academic Press
- Gergen, M.M. and Gergen, K.J. (2000). Qualitative inquiry: Tensions and transformations. Denzin, N.K. & Lincoln, Y.S. (Eds.) (2000) *Handbook of qualitative research*. 2nd edition. Thousand Oaks, CA: Sage.
- Gergen, M.M. & Gergen, K.J. (2003). *Social construction: A reader*. Thousand Oaks, CA: Sage.
- Gergen, K.J. & Gergen, M. (2004). *Social construction: entering the dialogue*. Chagrin Falls, OH: Taos Institute Publications.
- Gergen, K.J., Cisneros-Puebla & Fox, R.B. (2008). The deconstructive and reconstructive faces of social construction. *Forum qualitative social research*. January 2008, Vol. 9, No. 1, Art. 20
- Giddens, A. (1991). *Modernity and self-identity, Self and society in the late modern age*. Stanford, CA: Stanford University Press.
- Gilbert, P. and Procter, S. (2006). Compassionate Mind Training for People with High Shame and Self-Criticism: Overview and Pilot Study of a Group Therapy Approach. *Clinical Psychology and Psychotherapy*. 2006, Vol. 13, pp. 353-379, retrieved from www.interscience.wiley.com, DOI: 10.1002/cpp.507

- Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin Group.
- Gordon, T. (1970). *P.E.T. Parent Effectiveness Training : The tested new way*, French translation by Roy, J. & Lalanne, J. *Parents efficaces, une autre écoute de l'enfant*. France : Marabout.
- Gross, R.D. (1992). *The psychology: Science of mind and behaviour*. 2nd edition. London, UK: Hodder & Stoughton.
- Hall, Stuart (1992). *The question of cultural identity in modernity and its future*. Cambridge: The Open University.
- Hanisch, C. (1970). The personal is political. In Firestone, S. & Koedt, A. (Eds.) *Notes from the second year: Women's liberation*. New York, NY: Radical Feminism.
- Harper, C. (2007). *Intersex*. Oxford, UK: Berg.
- Harré, R., Moghaddam, F.M., Pilkerton Cairnie, T., Rothbart, D. & Sabat, S.R. (2009). Recent advances in Positioning Theory. *Theory Psychology*. 2009, Vol. 9, No. 5
- Harré, H. and Van Langenhove, L. (Eds.) (1999). *Positioning theory: Moral contexts of intentional action*. Oxford, UK: Blackwell Publishers.
- Hart, P. (Director) (2010). *Orchids, my intersex adventure*.
- Hassall, R., Rose, J. & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: the effects of parental cognitions in relation to child characteristics and family support. *Journal of intellectual disability research*. June 2005, Vol. 49, Part 6, pp. 405-418.
- Hastings, R.P. & Taunt, H.M. (2002). Positive perceptions in families of children with developmental disabilities. *American journal on mental retardation*. March 2002, Vol. 107, No. 2, pp. 116-127.
- Hastings, R.P. & Brown, T. (2002a). Behaviour problems of children with autism, parental self-efficacy, and mental health. *American journal on mental retardation*. May 2002, Vol. 107, No. 3, pp. 222-232.
- Herzog-Diem, R. & Huber, S. (2008). *Les groupes d'entraide autogérés: Se soutenir mutuellement pour aller mieux*. Zurich, Switzerland : Beobachter-Buchverlag/Axel Springer Schweiz AG.
- Holt, J. (1964/1982). *How children fail*. London: Penguin Books.
- Holt, J. (1967/1983). *How children learn*. Middlesex: Penguin Books.
- Hopkins, L. (2005b). *Creating an Activist Voice: Re-storying the Self in the Light of Contemporary Feminist Understandings of Power and Subjectivity*.

Retrieved from <http://www.bridgew.edu/soas/jiws/May01/Lekkie%20Hopkins.pdf>.

Hughes, C. (2002). *Key concepts in feminist theory and research*. Thousand Oaks, CA: Sage.

Husserl, E. (1931). *Cartesian meditations*. Dordrecht: Kluwer.

Jenkins, A. (2009). *Becoming ethical: A parallel, political journey with men who have abused*. Lyme Regis, UK: Russel House Publishing.

Johnston, C., Hessel, D., Blasey, C., Eliez, S., Erba, H., Dyer-Friedman, J., Glaser, B. & Reiss, A.L. (2003). Factors associated with parenting stress in mothers of children with Fragile X syndrome. *Developmental and behavioural paediatrics*. August 2003, Vol. 24, No. 4, pp. 267-275.

Joseph Di-Caprio, J. (2010). Counseling parents of difficult adolescents. *Minnesota Medicine*. 2010, Vol 93, Nr. 9, pp.41-44.

Joye, Charles (Ed.) (2012). *Handicap et diagnostic à l'aube de la vie: espoir ou derive? Regards croisés sur le diagnostic préimplantatoire*. Chene-Bourg, Switzerland: Editions Medecine et Hygiene.

Karkazis, K. (2008). *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Durham and London: Duke University Press.

Kleinman, A. (1988). *The illness narratives: Suffering, healing & the human condition*. USA: Basic Books, Perseus.

Lakoff, G. & Johnson, M. (1980). *Metaphors we live by*. Chicago: University of Chicago Press.

Lakoff, G. (1987). *Women, fire, and dangerous things: What categories reveal about the mind*. Chicago: University of Chicago Press.

Lewis, M. (1993). Self-Conscious Emotions: Embarrassment, Pride, Shame, and Guilt. *Handbook of Emotions*. Chapter 39. Retrieved from www.Wheaton-Edu

Lindley S., K. (2011) *Qu'est-ce que je ne dois pas entendre! Témoignages de mères*, Geneva : TT Spirit Ltd.

Lipsitz Bern, S. (1993). *The lenses of gender: Transforming the debate on sexual inequality*. New Haven and London: Yale University Press.

Lock, A. & Strong, T. (2010). *Social constructionism: sources and stirrings in theory and practice*. Cambridge, UK: Cambridge University Press.

Lysack, M. (2002). From monologue to dialogue in families: Internalized other interviewing and Mikhail Bakhtin. *Sciences pastorals/Pastoral Sciences*. 2002, Vol. 21, No. 2, pp. 219-244.

- Manné, J. (2006). *Le dialogue intérieur au quotidien*. Geneva, Switzerland : Jouvence.
- Marzari, M. (1999) Waiting for the author. In McNamee, S. & Gergen, K.J. *Relational responsibility: Resources for sustainable dialogue*. Thousand Oaks, CA: Sage. Chapter 18, pp. 187-196.
- May, T. (2005). *Gilles Deleuze, an introduction*. New York, NY: Cambridge University Press.
- May, T. (2006). *The philosophy of Foucault*. Chesham, Bucks: Acumen Publishing Ltd.
- McNamee, S. & Gergen, K.J. (1992). *Therapy as social construction*. Thousand Oaks, CA: Sage.
- McNamee, S. & Gergen, K.J. & Associates (1999). *Relational responsibility: Resources for sustainable dialogue*. Thousand Oaks, CA: Sage.
- McNamee, S. (in press). Constructing Values and Beliefs: A Relational Approach to Sustainable Development. In J. Appleton (Ed.), *Including Attitudes and Values in Sustainability Development Research*. New York: Routledge.
- McNamee, S. (2010) Reconstructing therapy in a postmodern world: Relational resources. In Goncalves, O. and Goncalves, M (Eds.) 2010. *Abordagens construcionistas a psicoterapia* (Constructionists approaches to psychotherapy). Coimbra, Portugal:Quarteto.
- McNamee, S. (2008) *Transformative dialogue: Coordinating conflicting moralities*. The Lindberg Lecture 2008.
- McNamee, S. (2004) Social construction as practical theory, Lessons for practice and reflection in psychotherapy. Paré, D. and Larnier, G. (2004) *Critical knowledge and practice in psychotherapy*. New York: Haworth Press.
- McNamee, S. & Schotter, J. (2004). Dialogue, creativity, and change. In Anderson, R., Baxter, L. and Cissna, K. (Eds.) *Dialogic approaches to communication*. Thousand Oaks, CA: Sage. Pages 91-104.
- McNamee, S. (2000). The social poetics of relationally engaged research: Research as conversation.(Die soziale Poesie beziehungsengagierter Forschung as Gespräch.) In Deissler, K.G. & McNamee, S. (Eds.) *Phil und Sophie auf der Couch: Die soziale Poesie therapeutischer Gespräche*. Heidelberg, Germany: Carl Auer Systeme Verlag. Pages 146-156.
- McNamee, S. (1996). Therapy and identity construction in a postmodern world. In Grodin, D. & Lindlof, T. (Eds.) *Constructing self in a mediated world*. California: Sage. Pages 141-155.

- McNamee, S. (1989). Challenging the patriarchal vision of social science: Lessons from a family therapy model. In Carter, K. & Spitzack, C. (Eds.) *Doing research on women's communication: Perspectives on theory and method*. NJ: Ablex. Pages 95-117.
- Moir, A. & Jessel, D. (1989). *Brainsex*. London: Mandarin
- Money, J. and Ehrhardt, A.A. (1972). *Man & Woman, Boy & Girl: The differentiation and dimorphism of gender identity from conception to maturity*. Baltimore and London: The John Hopkins University Press.
- Munt, S.R. (2007). *Queer attachments: The cultural politics of shame*. Aldershot, Hamps: Ashgate Publishing Ltd.
- Meyerhoff, B. (1978). *Number Our Days*. Simon and Schuster.
- Nersessian, N. J. (2008). *Creating scientific concepts*. Cambridge, MA: Massachusetts Institute of Technology
- Niedenthal, P.M., Tangney, J.P. and Gavanski, I. (1994). "If Only I Weren't" Versus "If Only I Hadn't": Distinguishing Shame and Guilt in Counterfactual Thinking. *Journal of Personality and Social Psychology*, 1994, Vol. 67, No. 4, pp.585-595
- Northrup, C. (2006). *The wisdom of menopause*. New York, NY: Bantam Dell.
- Ogilivy, J. (1995). *Living without a goal: finding the freedom to live a creative and innovative life*. New York, NY: Doubleday.
- Paré, D.A. (1995). Of families and other cultures: The shifting paradigm of family therapy. *Family Process*, Vol. 34, No. 1, pp. 1-19.
- Parker, J. & Parker, P. (Eds.) (2002). *The official parent' sourcebook on Klinefelter syndrome: A revised and updated directory for the internet age*. San Diego, CA: Health Care / ICON Health Publications.
- Paryas, P.M. (1993). Dialogism. In Makaryk, I.R. (Ed.) *Encyclopedia of contemporary literary theory: Approaches, scholars, terms*. Toronto, Canada: University of Toronto Press.
- Payne, M. (2000). *Narrative therapy*. Thousand Oaks, CA: Sage.
- Penn, P. (2009). *Joined imaginations, Writing and language in therapy*. Chagrin Falls, OH: Taos Institute Publications.
- Pinkola Estés, C. (1992). *Women who run with the wolves*. New York, NY: Ballantine Books.
- Pinnegar, S. & Daybes, J. G. (2007). Locating Narrative Inquiry historically. In Clandinin, D. J. (2007) (ed) *Handbook of Narrative Inquiry Mapping a methodology*. Thousand Oaks, CA: Sage.

Powell, J. (1997). *Derrida for beginners*. New York, NY: Writers and Readers Publishing.

Quinn, R.E., Dutton, J.E. & Spreitzer, G.M. (2004). *Reflected best self exercise: Assignment and instructions to participants*. Michigan: Ross School of Business, Positive Organizational Scholarship. Accessed on November 29, 2007.

Rabinow, P. (1984). *The Foucault reader: An introduction to Foucault's thought*. New York, NY: Penguin.

Rackham, N. and Morgan, T. (1977). *Behavioural analysis in training*. New York, NY: McGraw-Hill.

Redstone, A., Holmgren, A. and Walther, S. (In press) *Context and Discourse Map*. The Institute of Narrative Therapy, United Kingdom.

Rich, A. (1972). When we dead awaken: Writing as re-vision. *College English*. Women, writing and teaching. Oct. 1972, Vol. 34, No. 1, pp. 18-30.

Rich, A. (1980). Compulsory heterosexuality and lesbian existence. *Signs*. Women, sex and sexuality Summer 1980, Vol. 5, No. 4, pp. 631-660.

Rich, A. (1986). *Blood, bread, and poetry*. Ontario, Canada: Penguin Books Canada Ltd.

Rich, A. (1991). Claiming an education. *Conversations: Reading for writing*. 2nd edition. Seizer. J. New York, NY: Macmillan Publishing Company.

Rich, A. (1977). *Of woman born: Motherhood as experience and institution*. London, UK: Virago Press.

Richardson, R. L. and Adams St Pierre, E. (2005). Writing: A method of inquiry. In N Denzin & Y. Lincoln (Eds.). *The Sage handbook of qualitative research*. 3rd edition. Thousand Oaks, CA: Sage. Pp. 951-978.

Robb, J. & Letts, H. (1997). *Creating kids who can concentrate : Proven strategies for beating ADD without drugs*. Rydalmere, NSW : Hodder and Stoughton.

Rosenberg, M. B. (1999). *Les mots sont des fenêtres (ou des murs) Introduction à la communication non-violente* (French translation of *Nonviolent communication: A language of compassion*. St. Julien-en-Genevois, France : Editions Jouvence.

Rousseau, J. J. (1762). *Emile or Education*. Freebooks. Retrieved on March 2, 2013.

Rowan, J. (1990). *Subpersonalities: The people inside us*. London: Routledge.

- Ruesch, J. & Bateson, G. (2006). *Communication: The social matrix of psychiatry*. New Brunswick, USA and London: Transaction Publishers.
- Sampson, E. E. (2008). *Celebrating the other: A dialogic account of human nature*. Chagrin Falls, OH: Taos Institute.
- Schaffer, H.R. (1996). *Social development*. Oxford, UK: Blackwell Publishing.
- Scheff, T.J. (1997). *Emotions, the social bond, and human reality: Part/whole analysis*. Cambridge UK: Cambridge University Press.
- Schmaman, F.D. & Straker, G. (1980). Counseling parents of the hearing-impaired child during the post-diagnosis period. *Language, speech, and hearing services in schools*. October 1980, Vol. XI, No. 4.
- Schneider, C.D. (1977). *Shame, exposure and privacy*. New York, NY: W.W. Norton & Company.
- Seifert, J. L. with Seifert, B.W. (2010). *After the diagnosis: Transcending chronic illness*. New York, NY: Simon & Schuster.
- Shakespeare, T. (2006). *Disability rights and wrongs*. Oxon, UK: Routledge.
- Skygger, R. & Cleese, J. (1983) *Families and how to survive them*. London, UK: Methuen.
- Smart, C. (2007). *Personal life: New directions in sociological thinking*. Cambridge, UK: Polity Press.
- Smith, P.K., Cowie, H. & Blades, M. (2003). *Understanding children's development*. 4th edition. Oxford, UK: Blackwell Publishing.
- Solomon, A. (2012). *Far from the tree: Parents, children, and the search for identity*. New York, NY: Scribner.
- Stein, A. & Plummer, K. (1994). "I can't even think straight" "Queer theory and the missing sexual revolution in sociology. *Sociological Theory*. July 1994, Vol. 12, No.2.
- Steiner, S. (2012). The five regrets of the dying. Retrieved from http://www.guardian.co.uk/lifeandstyle/2012/feb/01/top-five-regrets-of-the-dying?CMP=tw_t_iph
- Stephenson, J. (1992). The perspectives of mothers whose children are in special day classes for learning disabilities. *Journal of Learning Disabilities*, Volume 25, Number 8, pp. 539-543.
- Stuart, J. (2007). Work and motherhood: Preliminary report of a psychoanalytic study. *Psychoanalytic Quarterly*, Vol. 76, pp. 439-485.

Stone, H. & Stone, S.L. (1989). *Embracing our selves, The voice dialogue manual*. Novato, CA: Nataraj Publishing.

Stone, S. (1997/2000). *The shadow king: The invisible force that holds women back*. Lincoln, NE: iUniverse.com.

Sulloway, F.J. (1996). *Born to rebel, Birth order, family dynamics and creative lives*. New York, NY: Pantheon.

[The] Swiss Advisory Commission on Biomedical Ethics. (2012). *Attitude à adopter face aux variations du développement sexuel: questions éthiques sur l' 'intersexualité'*. Prise de position no. 20/2012, pp. 1-26.

Tannen, D. (1994). *Gender & discourse*. New York, NY: Oxford University Press.

Tannen, D. (1998). *The argument culture: Stopping America's war of words*. New York, NY: Ballantine Publishing.

Tannen, D. (2001). *I only say this because I love you: How the way we talk can make or break family relationships throughout our lives*. New York, NY: Random House.

Taylor, E. (1994). *The hyperactive child: A parents' guide*. London, UK: Optima.

Taylor, S. (2002). *Ethnographic research: A reader*. London: Sage.

The Boston Women's Health Book Collective (1971). *Our bodies, our selves*. New York, NY: Simon and Schuster.

Tilsen, J. (2010). *Resisting homonormativity: Therapeutic conversations with queer youth*. Taos Institute/ Tilburg University: unpublished doctoral dissertation.

Tomm, K. (undated) Internalized-Other Interviewing in Common language for psychotherapy (clp) procedure. Retrieved from www.commonlanguagepsychotherapy.org on October 14, 2012.

Tracy, J.L. and Robins, R.W. (2004). Putting the Self Into Self-Conscious Emotions: A theoretical model. *Psychological Inquiry*. 2004, Vol. 15, No. 2, pp. 103-125.

Vygotsky, L.S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press

Wade, A. (1997). Small acts of living: everyday resistance to violence and other forms of oppression. *Contemporary Family Therapy*. March, 1997, Vol. 19, No.1.

- Walter, S. (2010). *Hazards of externalisation as a tool, workshop notes of Ali Borden*. Sheffield, UK: The Institute of Narrative Therapy.
- Warner, M. (1976). *Alone of all her sex, The myth and the cult of the virgin Mary*. London, UK: Picador.
- Weingarten, K. (1998). The Small and the Ordinary: The Daily Practice of a Postmodern Narrative Therapy. *Family process*, Spring 1998, Vol. 37.
- Weingarten, K. (1999). The politics of illness narratives: Who tells, who listens and who cares? *Narrative Therapy and Community Work: A Conference Collection*. Vol.1, pp. 13-26. Adelaide, Australia: Dulwich Centre Publications.
- Weingarten, K. (2001). Making sense of illness narratives: Braiding theory, practice and embodied life in *Working with the stories of women's lives*. Adelaide, Australia: Dulwich Centre Publications.
- Weingarten, K. (2012). Understanding families struggling daily with the effects of health problems. *Friday Afternoon Series*. Adelaide, Australia: Dulwich Centre. Accessed on February 25, 2013 CET 14:30.
- Weisbord, M.R. (Ed.) (1992). *Discovering common ground: How future search conferences bring people together to achieve breakthrough innovation, empowerment, shared vision, and collaborative action*. San Francisco, CA: Berrett-Koehler
- Wertsch, J.V. and Tulviste, P. (1992). L.S. Vygotsky and Contemporary Developmental Psychology. *Developmental Psychology*. July 1992, Vol. 28, No. 4, pp. 548-557.
- White, M. & Epston, D. (1990). *Narrative means to therapeutic ends*. New York, NY: W.W. Norton & Company.
- White, M. (2005). *Workshop notes*. Retrieved from www.dulwichcentre.com.
- White, M. (2007). *Maps of narrative practice*. New York, NY: W.W. Norton & Company.
- Whitney, D. & Trosten-Bloom, A. (2003). *The power of appreciative inquiry: A practical guide to positive change*. San Francisco, CA: Berrett-Koehler.
- Winnicott, D.W. (1964). *The child, the family and the outside world*. London, UK: Penguin
- Winnicott, D.W. (1965a). *The maturational processes and the facilitating environment*. London: Hogarth
- Winnicott, D.W. (1965b). *The family and individual development*. London: Tavistock Publications.

- Winslade, J. & Monk, G. (1999). *Narrative counseling in schools, Powerful & brief*. Thousand Oaks, CA: Corwin Press, Sage.
- Winslade, J. & Monk, G. (2001). *Narrative mediation, A new approach to conflict resolution*. San Francisco, CA: Jossey-Bass.
- Winslade, J. & Monk, G. (2008). *Practicing narrative mediation, Loosening the grip of conflict*. San Francisco, CA: Jossey-Bass.
- Winter, K. (2011). *Annabel*. London, UK: Jonathan Cape.
- Wittgenstein, L. (1961). *Tractatus logico-philosophicus*. New York, NY: Routledge.
- Wittgenstein, L. (1953/2009). *Philosophical Investigations*. 4th edition. Chichester, UK: Blackwell Publishing Ltd.
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